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KNOWING OUR OWN MINDS: THE ROLE AND VALUE OF EXPERIENTIAL KNOWLEDGE IN MENTAL HEALTH RESEARCH

THESIS SUBMITTED FOR PHD BY PRIOR PUBLICATION

VOLUME ONE

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CENTRE FOR MENTAL HEALTH RESEARCH, SCHOOL OF HEALTH SCIENCES

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VOLUME TWO: Published papers submitted for this PhD by Publication.

**THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED
FOR COPYRIGHT REASONS:**

p. 36, Cartoon by Merinda Epstein

p. 150+, reports and articles:

Faulkner, A. and Layzell, S. (2000) *Strategies for Living: a report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.

Crawford, M. et al (2007) *Learning the lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder*. National Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health.

http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1404-083_V01.pdf

Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health*. Volume 13, Number 6, December 2004 , pp. 549-559(11)

Price K, Gillespie S, Rutter D, Dhillon K, Gibson S, Faulkner A, Weaver T, Crawford MJ. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health* 18, 467–475

Faulkner, A., Gillespie, S., Imlack, S., Dhillon, K. and Crawford, M. (2008) Learning the Lessons Together. *Mental Health Today*, February, 24-26.

Faulkner, A. & Basset, T. (2012) A helping hand: taking peer support into the 21st century, *Mental Health and Social Inclusion*, Vol. 16 (1), pp.41 – 47.

Faulkner, A. and Basset, T. (2012) A long and honourable history. *The Journal of Mental Health Training, Education and Practice*, Vol. 7: 2, pp.53 –59.

Faulkner, A. (2012) The Right to Take Risks: service users' views of risk in adult social care. *The Journal of Adult Protection* Vol. 14 (6), pp.287 – 296. [Emerald Literati Highly Commended paper]

10. Faulkner, A. (2005) Institutional Conflict: the state of play in adult acute psychiatric wards. *The Journal of Adult Protection* 7 (4), 6-12.

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Last but not least, to Catherine my partner: love and thanks for your support and good humour through difficult times. It's your turn next!

Declaration

I grant powers to the University Librarian to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

Alison Faulkner, December 2016

ABSTRACT

This PhD thesis by prior publication describes a journey through the author's experiential knowledge and research development to a position where an understanding of this contribution is achieved with the assistance of emancipatory and standpoint research paradigms. The ten papers submitted as part of this thesis span a total of 12 years and a range of approaches including user-led or survivor research, user-controlled research and service user involvement in research. All of these terms are explored in relation to the ten publications for the different emphasis given to experiential knowledge and the relative power which that knowledge can attain.

The research establishes service users/survivors as researchers and as the 'knowers' of mental distress, of mental health services and of their(our) discriminated status within society, presenting critical perspectives on mainstream mental health services and treatments. A central theme is the significance of relationship and connectedness (often established through different manifestations of 'peer support') in the development of experiential knowledge.

This body of knowledge represents both a contribution and a challenge to mainstream mental health knowledge and mental health research. Issues of power and identity run through much of this thesis; the dominant psychiatric discourse leaves little space in mental health research for the knowledge that comes from direct experience. Nevertheless, the papers demonstrate that survivor research has carved itself a significant space for experiential knowledge over the last couple of decades, and it is hoped that the newly-framed discipline of Mad Studies will further validate that space and the knowledge(s) that can grow within it.

INTRODUCTION

In this thesis, I intend to demonstrate the significant contribution that I have made to mental health research and to survivor research and to place this thinking within the context of dominant (positivist) and emerging (survivor) research paradigms. This body of work forms part of a wider individual and collective project to bring the views and experiences of people with experience of mental distress to the fore, to give validity and space to our stories through the prism of survivor research and in the process, to transform our understanding of what constitutes valid, meaningful mental health knowledge. Research is not the only - perhaps not even the best - way of bringing about change, but, to quote a pioneer survivor researcher Viv Lindow (2001), it

'..has its part to play in developing solidarity among psychiatric system survivors and helping to raise the expectations of those who have been 'educated' to live with an unacceptable quality of life. Survivor research can be a small but key part in the move to seize freedom within an oppressive and excluding society.' (Lindow, 2001, p.145)

Chapter One describes the main concepts explored throughout this thesis: experiential knowledge; service user/survivor narratives; survivor research; standpoint theory; identity and power. Chapter Two describes the research methods and findings behind the published reports and papers that form the basis of this thesis. The narrative begins with the report 'Strategies for Living: a report of user-led research into people's strategies for living with mental distress', published by the Mental Health Foundation (UK mental health charity), which is the starting point for the ideas developed over the subsequent papers and years. Chapter Three presents a critical appraisal of the predominantly qualitative methodologies represented in the papers. In Chapter Four, I draw the themes together and consider the overall contribution made by the publications submitted to mental health knowledge and knowledge production, and their impact on mental health research. I then address the role and value of experiential knowledge before finally reflecting upon my development as a researcher and the experience of undertaking this PhD.

The publications chosen as the basis for this publication demonstrate the development in my thinking about issues such as: the role of identity and power in research and the

foregrounding of the perspectives of service users and survivors. A thread running through the thesis is the desire to let people deemed 'mentally ill' to speak: to tell their stories without the constraints of diagnosis or stigma and to balance 'the overwhelming majority of material written about those who are labelled mad by those who do the labelling and those who study them' (Crepaz-Keay and Kalathil, 2013, <http://global.oup.com/booksites/content/9780199579563/narratives/>).

I explore the role played by survivor (user-led) research that seeks to place the individual story as central. This will entail exploration of the role of identity and the significance of power (and where power lies) in creating and building on those stories to raise awareness and empowerment among service users and create new service user/survivor initiated knowledge.

In a number of related areas of mental health experience, care and treatment (inpatient care, strategies for living, peer support, risk and safety), I have sought to place the service user perspective as central, to explore the origin of these themes within service user action and activism, and demonstrate the ways in which these ideas are often incorporated and changed by mental health services and research led by (mainly) professional clinical academics.

I explore the potential of service user-led research to empower both individuals and communities in their relationship with mental health services, and to therefore change the dynamic between service users and researchers and services. I place a particular emphasis on the role of peer support or relationship and connectedness in locating the experiential knowledge of service users and survivors in the establishment of a social movement.

THE PUBLICATIONS SUBMITTED FOR THIS THESIS

Reports

1. Faulkner, A. and Layzell, S. (2000) *Strategies for Living: a report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.
2. Crawford, M. et al* (2007) *Learning the lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder*. National

Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health. *18 authors listed.

3. Faulkner, A. (2010) *Changing Our Worlds: Examples of user-controlled research in action*. Eastleigh: INVOLVE.

Papers

4. Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health*. Volume 13, Number 6, December 2004 , pp. 549-559(11)
5. Price K, Gillespie S, Rutter D, Dhillon K, Gibson S, Faulkner A, Weaver T, Crawford MJ. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health* 18, 467–475
6. Faulkner, A., Gillespie, S., Imlack, S., Dhillon, K. and Crawford, M. (2008) Learning the Lessons Together. *Mental Health Today*, February, 24-26.
7. Faulkner, A. & Basset, T. (2012) A helping hand: taking peer support into the 21st century, *Mental Health and Social Inclusion*, Vol. 16 (1), pp.41 – 47.
8. Faulkner, A. and Basset, T. (2012) A long and honourable history. *The Journal of Mental Health Training, Education and Practice*, Vol. 7: 2, pp.53 – 59.
9. Faulkner, A. (2012) The Right to Take Risks: service users' views of risk in adult social care. *The Journal of Adult Protection* Vol. 14 (6), pp.287 – 296. [Emerald Literati Highly Commended paper]
10. Faulkner, A. (2005) Institutional Conflict: the state of play in adult acute psychiatric wards. *The Journal of Adult Protection* 7 (4), 6-12.

The publications constitute a diverse range of themes and methods with a number of common threads, which are drawn out in Chapter One. The table below summarises the different themes and methods addressed in each.

TABLE 1.1 SUMMARY OF PUBLICATIONS SUBMITTED FOR THIS THESIS

Report/ Paper	Theme	Approach taken	Degree of involvement / Context
Report 1.	'Strategies for living' - i.e. ways of coping with or managing mental distress	Qualitative: depth interviews	User-led research / Voluntary sector
Report 2.	Services for people diagnosed with personality disorder	<ul style="list-style-type: none"> • Qualitative: depth interviews • Part of a large mixed methods evaluation 	Service user involvement in research / NIHR programme grant
Report 3.	User-controlled research	<ul style="list-style-type: none"> • Multiple case studies 	User-led study of user-controlled research / NIHR Advisory Group
Paper 4.	Service user involvement in mental health research	<ul style="list-style-type: none"> • Review paper 	Collaborative paper: clinical researcher with service user / joint authors initiative
Paper 5.	Services for people diagnosed with personality disorder	<ul style="list-style-type: none"> • Qualitative: depth interviews • Part of a large mixed methods evaluation 	Service user involvement in research / NIHR programme grant
Paper 6.	Services for people diagnosed with personality disorder	<ul style="list-style-type: none"> • Qualitative: depth interviews • Part of a large mixed methods evaluation 	Service user involvement in research / NIHR programme grant
Paper 7.	Peer support	<ul style="list-style-type: none"> • Qualitative: focus groups 	User-led / Voluntary sector
Paper 8.	Peer support	<ul style="list-style-type: none"> • Review paper 	User-led / Voluntary sector
Paper 9.	Service users' views of risk	<ul style="list-style-type: none"> • Qualitative: depth interviews and focus group 	User-led / Voluntary sector
Paper 10.	Acute inpatient care	<ul style="list-style-type: none"> • Review paper, personal reflection 	User-controlled / own initiative

A NOTE ON LANGUAGE

One thing I know for certain is that we will never agree on the language we use in mental health. A number of different terms are used interchangeably in this thesis. What we call ourselves - and whether we have the power to call ourselves anything - is important, although it can change in relation to time and place and context. Sometimes I refer to myself as a 'service user' and sometimes as a 'survivor'. As I move further away in time from my direct use of services, I feel less comfortable with the term 'service user'. For all that it is controversial, depersonalising and potentially limiting, it is the term most commonly used to refer to people who are in receipt of mental health and/or social care services in the UK and so it is used in this thesis. Many people who have experienced mental ill health define themselves as 'survivors', referring not only to the effects of mental distress in all its forms, but also to their survival of the psychiatric system (Stickley, 2006). I often call myself a service user/survivor in the course of my work as if I wish to have a foot in both camps. (This is explored more in Positioning Myself (page 8) and in Chapter One in relation to identity and power).

In a similar way, a number of terms will be used to refer to 'mental illness', 'mental distress' and 'mental health problems'. I balk at the term 'mental illness' because of its association with brain disease, diagnosis and the biomedical model. Many voluntary sector organisations use 'mental health problems' or 'difficulties' which I use too in many places throughout this thesis. The term 'mental distress' is used sometimes, and although this may sound different, it, too, refers to the full range of mental health problems including those defined as mild, moderate, severe and acute. In the words of Kalathil (2011a) the term 'mental distress' 'straddles diagnostic, managerial and social categorisations of mental and emotional crises, and allows people to define them according to their specific contexts and experiences' (Kalathil, 2011a, p.11).

And finally, there is 'madness' and its mixed connotations: of unreason and insanity and yet of reclaiming the language of our history, in the tradition of gay pride. The term 'Mad' has been used increasingly in recent years with the advent of 'Mad Pride' and the newer academic discipline of 'Mad Studies'. Some people do find it offensive (Beresford et al, 2016), but I find it challenging and fun. Mary O'Hagan, in her memoir 'Madness Made Me'

(2014), says of reclaiming the word 'madness': 'we have removed it from the trash can of insults and polished it to reveal a unique pattern of human experiences' (O'Hagan, p.7).

POSITIONING MYSELF

Owing to the nature of the research I am writing about and advocating in this thesis, it is essential that I position myself in relation to my research. It is a curious fact that undertaking a PhD is a profoundly individual activity, and yet the kind of research I am presenting here attempts to locate research within a wider community and social context. I have resisted doing a PhD for these very reasons, and find myself at times struggling with the individualistic nature of the endeavour and of its potential outcome.

Taking a reflexive approach means reflecting on our role and identity in the research, making ourselves aware of our own feelings, beliefs and expectations about the research and positioning ourselves in relation to the people whose worlds we are exploring. In this way we can begin to understand our relationship with the research both personally and professionally (Shaw 2010; Humphries, 2000b) and to explore and understand our identity and power in relation to those being researched (Beresford 2005; Alvesson and Skoldberg, 2009; Carr, 2013). These themes are explored further in Chapters One and Four.

We all hold a number of different identities based on aspects of ourselves and our backgrounds, our roles in our communities or in society. For the purposes of this thesis, it is my identity as researcher and service user/survivor that I am foregrounding, but I also value my identity as a sister, lover, friend and as a member of another minority group: the lesbian, gay, bisexual and transgender (LGBT) Community. Importantly, I also identify as white and middle class, aspects of my identity which offer me particular privileges in society and place me in a position of power in relation to people who identify as black or from minority ethnic and working class communities.

My research and psychiatric careers began at about the same time. After periods of depression and self-harm as a teenager, I had my first 'breakdown' at the age of 20 whilst studying for a psychology degree in London. I took my first year exams whilst in an inpatient unit and went on to have a couple of years of therapy on the NHS. At this time I successfully avoided diagnosis and medication, being deemed to be in the midst of an 'adolescent crisis'.

Following my MSc in Cardiff in 1984, I went on to work as a researcher at Mind (investigating the use of section 136 of the Mental Health Act, 1983) and thence to train in

qualitative methods at Social and Community Planning Research (now the National Centre for Social Research, NatCen). I also worked at a number of mental health charities: the Centre for Mental Health and the Mental Health Foundation, before opting to go freelance in 2002. I deliberately did not attempt an academic career because I felt that I would not be able to cope with the pressure alongside the belief that I would need to conceal any mental health difficulties I might be having. I am sure I am not alone in making this kind of decision, nor in finding my decisions influenced by these issues (see, for example, Rose, 2003a; Jones and Brown, 2013).

My second breakdown occurred in 1997 at the start of the first project discussed in this thesis, 'Strategies for Living' and whilst working at the Mental Health Foundation. This time I could not avoid the consequences of hospitalisation, diagnosis, medication, humiliation and stigma, whilst at the same time coming to identify more closely with the people with whom I was working. I began to see myself as a 'mental health service user': the term seemed accurate as it described what I was doing. Over the course of the following few years, I had six or seven admissions to hospital and several attendances at A&E for self-harm. Life took on a strange pattern: I continued to work in between these incidents of distress and gradually the gaps between crises became longer. I have never personally identified with a diagnosis, although my records suggest that it changed during this time from 'recurrent depression' to 'depression with borderline features' to borderline personality disorder (or, as my psychiatrist called it: 'emotionally unstable personality').

'Strategies for Living' embraced me and I embraced it; I felt that the team and all those associated with it supported me as much as I could ever support them. I fully realised and lived the experience of identifying with the people we were researching with, in an echo of the experience related by Kathryn Church in her book 'Forbidden Narratives; Critical Autobiography as Social Science' (Church, 1995).

During the course of my experiences of both using mental health services and of doing research, a number of changes to my thinking about research have occurred. I came first to value qualitative methods before I went on to understand the value and the need for those of us with direct experience of mental health problems, to assume the power and authority to do the research ourselves. In my two years of doing qualitative research at NatCen, I

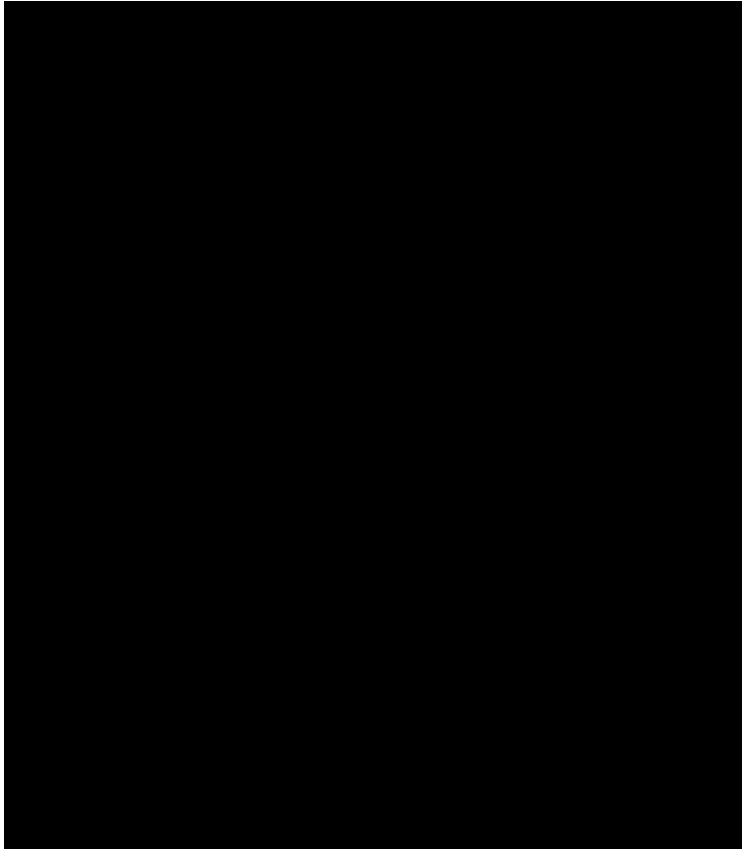
believed in the researcher's responsibility (and ability) to maintain a degree of 'objectivity'. However, a number of experiences challenged and changed my thinking, aside from my own mental distress.

In the mid 1980s I worked on a project where I was trying to interview people recently detained by the police under section 136 of the Mental Health Act (1983), without much success. Turning up in the psychiatric hospital with my briefcase and questionnaire and endeavouring to engage people in severe distress felt profoundly uncomfortable. (Never mind the fact that I occasionally thought of myself as that patient. For I, too, had once been taken by the police from a public toilet to hospital.) The few people I did manage to talk to had distressing stories to tell and had often not been believed. It was hard to know how to report this and remain true to research that had been approved by an ethics committee, and yet which at times felt profoundly unethical.

Another incident that affected my thinking occurred when I was an inpatient in the late 1990s. I was asked if I minded answering some questions for a research project; being a researcher myself, I agreed. I have no memory of the nature or status of this research, but I do remember stopping when I realised the nature of the questions. I was experiencing being on the receiving end of what I had been trying to do in the section 136 research. It was deeply unpleasant having these intrusive personal questions fired at me, with little preamble or attempt to build up trust between us, and when I was in a distressed state. It was a powerful insight into what it felt like to be the 'researched' object.

I felt then that there had to be other ways of doing research: ways in which, not only the views of service users could feed into the design of the research, but in which the research participants were given more power and control over the telling of their stories. I can't pretend that I have always managed to achieve this in my research, but I do believe it is both possible and essential if we are to find more meaningful solutions or supports for people in distress. We are none of us 'service users' by choice; this is shorthand for describing people whose mental distress brings them into contact with mental health services. I do not want to end my days as a 'service user', but as a woman, a researcher, a cat lover and a lover, sister, friend. I certainly want no part of the diagnoses I have had the

misfortune to become familiar with. But power sometimes takes away our ability or capacity to name ourselves. Perhaps in writing this thesis, I am taking back some of that power.



CHAPTER ONE: THE CONCEPTS

In this Chapter, I outline the main concepts explored through this thesis: experiential knowledge; service user/survivor narratives; survivor research; standpoint theory; identity and power. These concepts are explored in different ways and to different extents in the nominated publications and form the backbone to my thinking and my development as a researcher over the last twenty five years.

1.1 EXPERIENTIAL KNOWLEDGE

Experiential knowledge in one way or another runs throughout the body of work featured in this thesis. It is fundamental to my overall critique of mainstream research and the quest for the greater acknowledgement and involvement of mental health service users and survivors in research and in the production of knowledge (Beresford, 2005; Beresford and Boxall, 2013). Experiential knowledge achieves, or is accorded, different degrees of prominence in the different pieces of work largely due to the practical execution of the concept of user 'involvement' and/or control (explored further in 1.3).

Borkman (1976; 1990) describes experiential knowledge as based on having undergone specific and affecting life experiences, arguing that it is '...specialized knowledge, grounded in an individual's lived experience' (Borkman, 1990, p.3). Borkman goes on to describe 'experiential authority' as legitimising or giving credibility to the knowledge gained through personal experience. Although writing predominantly about self-help, she traces the origins of experiential knowledge back to the civil rights movements of the 1960s and 1970s, where people's experiential authority 'gave them the power among themselves to take their own and their peers' stories seriously' (Borkman, 1990, p.7). This concept and its origins are central to this thesis.

Experiential knowledge is at the core of peer support and self-help, where people share their experiences and strategies and learn from each other (Borkman, 1990; Seeborn et al, 2013; Munn-Giddings et al, 2009). People come to acquire positive 'experiential authority' through the personal experience of living through and with mental distress, and through the practice of sharing and exchanging experiential knowledge and expertise (often through service user and survivor self-help and peer support groups) (Noorani, 2013). Experiential knowledge involves some degree of inter-connectedness and reflection on one's

experiences such that a body of knowledge is established and legitimised over time. As Borkman (1990) points out, experiential knowledge is more than the raw experience of the individual:

'The raw experience of an individual has to undergo a reflexive process before it is changed into experiential knowledge... one has undergone a reflexive internalized process that resulted in some awareness of the situation' (Borkman, 1990, p.25).

Borkman (1990) also talks of 'successful, established' self-help groups that 'create, test, use and disseminate a body of experiential knowledge' to the extent that they may be regarded as 'experiential learning communities'. Examples of this in mental health can be seen in the establishment of the Hearing Voices Network (HVN) and the early work on self-advocacy, self-harm and eating distress originating from the service user/survivor organisation Survivors Speak Out (SSO), the National Self-Harm Network and, more recently, Harmless (Pembroke, 1994, 1996; Harmless, 2009).

In terms of the status of this knowledge, the mediating element is power, since professional knowledge is accorded a higher status/authority within society, within research and within the mental health system in particular (Beresford and Boxall, 2013). The dominant paradigm in mental health, which is predicated on the existence of disease of assumed biomedical origins, results in an emphasis on technical expertise and the use of an individualist framework which 'not only obscures people's social-material world in our understanding of people's experiences, behaviour and distress, it also *marginalises the lived experience and knowledge of those deemed mad*' (Coles et al, 2013, p.vii - my emphasis). Jones and Brown (2013) note the effect of professionalisation/clinicalisation of mental health on service user/survivor knowledge: "the power to generate knowledge about particular phenomena is allotted ... to academics that have specifically been trained to 'treat' individual abnormality or pathology ... mental health research in the US remains almost wholly dominated by clinically trained investigators." (p.7). Consequently, they say, the mental health discourse is dominated by discussion of clinical treatments and rehabilitation, to the exclusion of the many other ways in which people might understand and express their mental distress.

Within a self-help or peer support group, this will not necessarily be the case; in fact, it may well be reversed and experiential knowledge used to challenge the knowledge based on professional learning (Noorani, 2013; Borkman, 1990; Seebohm, et al, 2013).

More importantly for the purposes of this thesis, experiential knowledge is the 'bedrock' of survivor research (Sweeney, 2013), in the collective move to challenge the exclusion of service user and survivor voices from mainstream research and knowledge production. The experiential knowledge gained from direct personal experience of the (mental health) issues under study is what distinguishes survivor research and emancipatory research (Beresford, 2005). Glasby and Beresford (2006) ask some fundamental questions about the nature of knowledge within a context based on evidence-based medicine and practice. In their view, neglecting the views and experiences of people who use health and social care services gives a *'false and potentially dangerous view of the world'* (Glasby and Beresford, 2006, p.271). They highlight the crucial contribution that 'experiential knowledge' has to bring to the evidence table, a theme taken up by many survivor researchers since (Sweeney, 2013; Rose, 2009; Russo, 2012; Faulkner and Basset, 2012).

However, to foreground experiential knowledge in research contradicts some of the basic tenets of traditional research, which claims to be neutral and objective in its search for knowledge and 'truth'. Experiential knowledge can be dismissed through claims that it is inherently individual, anecdotal or simply 'wrong' (Prior, 2003). In mental health we are also subject to claims that we are uniquely poorly placed to form understandings or theories about knowledge, given that we can be dismissed as fundamentally irrational by virtue of being deemed 'mad' (Rose, 2003a). Beresford (2005) points out that user controlled research is 'vulnerable to accusations of being weak, partisan and distorting' (p.8). It seems to me that we cannot underestimate the power of these attitudes running through many of the challenges to survivor research (Rose, 2014b; Turner and Beresford, 2005).

However, the counter to this is (at least) three-fold. Firstly, experiential knowledge has a significant contribution to make where some of the basic premises of professional knowledge are strongly contested. In mental health, the medical model of diagnosis and treatment is challenged by many service users and survivors, as well as by some critical psychiatrists and psychologists (Thomas, 2014; Carey and Pilgrim, 2010; Pilgrim, 2007). This,

in theory at least, opens up the space for experiential knowledge and for survivor researchers to develop their (our) theories. Research that enables us and our peers to reflect on our experiences and build and produce experiential knowledge as a means of both critique and empowerment is an essential development of our lived experience of mental distress. We need to (continue to) find more and better ways of both bringing individual experiences together and of being the 'creators of our own analysis and theory' (Beresford and Wallcraft, 1997; p.77), through building collective understandings of our experiences and adding to the broader mental health knowledge-base.

Secondly, as pointed out by Beresford (2005) and Russo (2012), the assumption underlying positivist research that the *greater* the distance from the experience under investigation makes the view more reliable, needs examining. What if, instead, the 'shorter the distance there is between direct experience and its interpretation ... the less distorted, inaccurate and damaging resulting knowledge is likely to be' (Beresford, 2005, p.7)? Russo (2012) emphasises the importance of imparting an insider perspective to research; for her, too, closeness to the subject of the research is beneficial to the research quality enhancing its validity.

Thirdly, a different positioning of experiential knowledge can enable and strengthen the inclusion and expression of diverse and marginalised voices, which tend to be neglected in mainstream research. As previously mentioned, an understanding of experiential knowledge has its roots in the civil and human rights movements of the 1960s and 1970s (Borkman, 1990; Noorani, 2013). Many took a predominantly rights based approach, as did the early survivor and service user campaigning groups in the 1980s, with the experiential knowledge based on a shared experience of oppression, discrimination or marginalisation (Emerick, 1996). This is key to the motivation behind much of the work to develop experiential knowledge through survivor research, and is a theme to which I will return later.

The key question for those of us who wish to foreground experiential knowledge is: *is it different from professional knowledge?* (and if so, in what ways is it different?). Noorani (2013) assumes that experiential knowledge is different in referring to its opposition to professional knowledge; he refers to its 'pragmatic' and holistic nature and its focus on the everyday needs of people in distress in relation to self-help and peer support groups where

such knowledge is generated. This reflects the concerns raised by service users about the mental health system's failure to address such issues as poverty, homelessness and, particularly, stigma and discrimination.

I would argue that experiential knowledge has the potential to transform the knowledge base for mental health, even (perhaps especially) within the self-help or peer support groups themselves (Seebohm et al, 2013; Seebohm et al, 2010). For it is from these often small and local roots that the flowers of change can grow. Beresford (2013) suggests that experiential knowledge has the potential to transform our understanding of helpful responses to madness and distress. He points to an emphasis on the value of peer support, self-management, holistic approaches, self-run schemes for personal support and user-controlled organisations and services. I would add to this the growth in alternative responses to crisis, an issue long campaigned for by service users and survivors. Seebohm et al (2013) further point to the role of self-help/mutual aid groups (groups in which the development of experiential knowledge is a core element) in enhancing mental wellbeing, particularly among black and minority ethnic communities who are often excluded from the experiential knowledge base of a predominantly white service user/survivor movement (Seebohm et al, 2010).

1.2 TELLING OUR STORIES: THE ROLE OF PERSONAL NARRATIVES

Finding our voices and telling our stories *on our own terms* has been central to the development of the service user/survivor movement, central to our shared history of organising for change (Costa et al, 2012). Sharing our stories with each other is a means through which we come to understand and recognise our own and others' expertise (Seebohm et al, 2013), and to redefine or rebuild our identities (Brown, 2008). There is a big difference between a psychiatric case history and a personal narrative (Costa et al, 2012; Morgan et al, 2016); not only is the owner and narrator of the story different but the story, too, takes a different course. The personal narrative is embedded within the political and social context of a person's life, it can document the different roles a person undertakes at different times in their lives and the story and the telling of it can change over time (Faulkner, 2010).

Experiential knowledge is founded upon our stories, our personal narratives of mental distress and our experiences of treatments and services within the context of our lives. As referenced earlier, Borkman (1990) said that we come to take our own and our peers' stories seriously in the process of empowerment and the claiming of experiential authority. This is central to the development of experiential knowledge and to the credibility of survivor research. There is power and empowerment to be found in the coming together of people with shared experiences of mental distress to share and listen to each other's stories. Our stories are the foundation stones upon which service user/survivor understandings, community knowledge and empowerment are built.

'Listening, really listening to someone is a way of helping them to feel, perhaps for the first time in their lives, they have value just as human beings. And until you know that you do have value, you have not got any tools with which to build your own recovery, however helpful professionals are.' (Hutchinson and Lovell, 2013, p.647)

Curiously, for a discipline concerned with people, psychiatry has traditionally neglected the individual story and sought instead to elicit information from individuals that will help to fit them into pre-defined categories or diagnoses (Russo, 2012; Russo and Beresford, 2014; Thomas, 2014). Psychiatry's need to diagnose and treat often closes us down and prevents us from telling our stories from our own perspectives. In addition, the underlying threat of coercion from the Mental Health Act (1983) within a risk-averse culture further silence us. The lack of continuity in mental health care also means that people are often required to keep retelling the 'negative storyline' of their experiences (Brown, 2008). Indeed, Morgan et al (2016) suggest that telling our stories 'is both a routine experience and an impossibility' (p.89). Within the context of a psychiatric interview, our stories are (re)interpreted through the fixed technical framework of diagnostic categories. There is little space for 'letting stories breathe' (Frank, 2010; Morgan et al, 2016).

Telling our stories is, arguably, the primary route to empowerment and recovery (Dillon and May, 2002; Thornhill et al, 2004; Brown, 2008; Hutchinson and Lovell, 2013).

'In this sharing of experience we are told new stories - counter-narratives which offer diverse representations of survival in adversity.' (Dillon and May, 2002, p.25)

'Indeed, it may be that the process of making sense of the experience in ways that are personally meaningful to the individual is one of the keys to recovery.' (Thornhill, Clare and May, 2004; p.194)

When the Recovery approach was originally founded, the opportunity for people in distress to tell our stories was central to its underlying principles (Deegan, 1996a). Recovery in mental health has been defined as being about building a meaningful and satisfying life, whether or not there are recurring or ongoing symptoms or mental health problems (see, for example, ImROC <http://imroc.org/>). However, many survivors consider that Recovery in the UK has been co-opted by services into something that no longer respects the individual's ownership of recovery and is instead used as a means and an excuse to close day services and discharge people out of secondary care (Rose, 2014a; Simpson et al, 2016). For the 'Recovery in the Bin' user-led Facebook group, recovery has been colonised and 'used to discipline and control those who are trying to find a place in the world, to live as they wish, trying to deal with the very real mental distress they encounter on a daily basis' (Recovery in the Bin, undated, home page: <https://recoveryinthebin.org/>). In addition, there are many service users who do not understand recovery in this way, or have not been exposed to this Recovery approach and hence do not see it as applying to them. More importantly, the Recovery approach has emerged within a white Western culture and society and has not incorporated the different visions of recovery coming from racialised communities (Kalathil, 2011b) or other marginalised groups.

Nevertheless, this link between personal narratives and recovery (however you understand the term recovery) is important. In her report on narratives of recovery and resilience among African, African Caribbean and South Asian women, Kalathil (2011b) described the finding that people's understandings of their recovery are 'intrinsically linked to the ways in which they make sense of their mental distress' (p.20) as the most important message of her study.

“...sometimes you can’t make sense of what has happened in your life unless you are actually telling somebody the story, you know, so re-living the story for me is always a healing experience for me. Even though I might feel that I am completely healed, you heal a bit more every time you tell the story...” [quoted in Kalathil (2011b) p. 20]

Significantly, both in this study and in the author's Report 1 (Strategies for Living), for many participants, the research interview was the first time they had been given the space in which to tell their story: 'This in itself, we believe, is a significant achievement of this project' (Kalathil, 2011b, p.76).

In his work with the Dulwich Centre Foundation in Australia where they use both narrative techniques and 'critical heritage practice', David Denborough (2014a; 2014b) takes these ideas a step further. He describes how the telling of stories and the listening to them can enable two processes of what he calls 'bridging the gap' to take place: first, between survivors and those who are doing the listening and second, between the personal and the social by placing the individual experience within its wider social and political context. Denborough suggests that narrative enquiry can enable a person to externalise and situate their experiences within a social and political context: that, often, our distress can be linked to experiences of 'personal tyranny and abuse' or understood within the shadow of 'broader social forces'. (p.72). He also emphasises the power of genuine, active listening.

'Sometimes we share our own experiences in ways that make it possible for other survivors to speak. We listen in ways that show we understand'. (Ibuka counselors, quoted in Denborough, 2014a, p.71)

Interestingly, this links with psychologist David Smail's concept of 'outsight', which he defines as 'taking account, both theoretically and practically, of the role of social factors in the generation of distress' (Smail, 2006, p.19). More than that, it is a process in which the person gains that 'outsight' themselves - demystifying, understanding and being able to place their own experiences within this wider context instead of rendering it an individual, isolated and psychologised experience. It speaks of power and empowerment, and in this vein, Smail talks of the role that clinical psychology could have in supporting and encouraging people's activism 'without taking it over' (p.20).

Within the emerging 'Mad Studies' project (e.g. LeFrancois et al, 2013) survivors are talking about the vital connection between individual experience and collective, socially situated knowledge(s) about oppression and discrimination.

'As we discover how particular experiences are mediated through social relations, we can connect the 'immediate' experience we started with to the larger social organization.' (Gorman, 2013; p.274)

Mad Studies has been described by Lucy Costa (2014) as 'an area of education, scholarship, and analysis about the experiences, history, culture, political organising, narratives, writings and most importantly, the PEOPLE who identify as: Mad; psychiatric survivors; consumers; service users; mentally ill; patients, neuro-diverse; inmates; disabled -to name a few of the "identity labels" our community may choose to use (Costa, 2014:

<https://madstudies2014.wordpress.com/2014/10/15/mad-studies-what-it-is-and-why-you-should-care-2/>). The importance of Mad Studies lies in the space it is opening up for us to develop our own theories, models and ideas about how we understand ourselves, or our experiences in relationship to mental health system(s), research and politics.

The project of survivor research is then, at least in part, to hear people's stories in meaningful ways, to enable silenced voices to speak from the margins and have the space to be heard (Carr, 2013). As pointed out by Wallcraft (2009), mental health service users have 'traditionally been excluded from creating the knowledge that is used to treat us, and many of us have suffered from the misunderstanding of our needs by people who have been taught to see us as by definition incapable of rational thought' (Wallcraft, 2009, p.133). So, in other words, it is not just about being heard, it is about being believed as 'credible knowers' (Radden, 2012). Russo and Beresford (2014) and Costa et al (2012) also emphasise the importance of service users and survivors ourselves becoming the 'knowers', rather than having the knowledge we have gained through our experiences appropriated, re-framed and alienated from us in the academic arena just as it is within the psychiatric framework. They argue for a different means of doing research, incorporating emancipatory methods, to ensure that participants retain power within the research process.

Some survivors have chosen to undertake an autoethnographic approach to exploring their experiences of madness and distress, an approach that explicitly places aspects of personal narrative against ethnographic analysis of culture and social context (Fabris, 2012; Ellis et al, 2011; Carr, 2013; Short et al, 2013). In this thesis, I touch on autoethnography in Chapter 3 when discussing Paper 10.

1.3 SURVIVOR RESEARCH

Survivor research (often referred to as service user or user-led research) is a term used increasingly over the last couple of decades to refer to research undertaken by mental health service users /survivors. There is no easy definition of survivor research, although many approaches to defining it are contained in the seminal work 'This is Survivor Research' edited by Sweeney et al (2009). For example, Beresford and Rose (2009) emphasise that survivor research has emancipatory purpose; i.e.

'it is committed to challenging the disempowerment of mental health service users/survivors and supporting them to have a greater say in their lives and influence in the world in which they live'. (Beresford and Rose, 2009, p.18)

They also highlight the endeavour amongst survivor researchers to reduce the power inequalities between the researchers and the researched. Sweeney (2009) additionally highlights the roots of survivor research within the service user/survivor movement, the role of empowerment and the ethics and values underpinning survivor research developed over the last decade or so by service user and survivor researchers (Faulkner, 2004a). For Russo (2012) survivor research is defined by the central role taken by experiential knowledge throughout the whole research process, from the design to the analysis and the interpretation of findings. Russo also highlights the challenge that survivor research presents to the bio-medical model of mental illness as a key identifier.

It is important to say a bit more about the emancipatory research paradigm because this is an important root of survivor research. Originating in the disabled people's movement, the focus is on researching disabling environments or a disabling society rather than the individual deficits of disabled people (Boxall and Beresford, 2013). Integral to the emancipatory paradigm is a challenge to academic or professional knowledge about disabled people, as is the accountability of researchers to organisations of disabled people; 'such research approaches are therefore openly partisan' (Boxall and Beresford, 2013, p.592). Tew et al (2006) talk of the 'emancipatory purpose' of mental health research: referring to how the research will produce evidence and theory that can enable service users and carers to:

- have a greater awareness of their situation so that they can make informed decisions and choices
- have more control over the direction of their lives
- participate more in social, economic and political life and can enable them, in conjunction with practitioners and members of the wider community, to:
- challenge stigma, injustice and social exclusion

(Tew et al, 2006, p.vi)

There is something of a tradition for survivor researchers (and emancipatory disability research) to adopt qualitative research methods because of the focus on hearing and respecting people's stories; as Barnes (2003) points out 'large scale surveys and detailed quantitative analyses have never captured fully the extent and complexity of the oppression encountered by disabled people'(p.10). Implicit in the requirement to hear and respect experiential knowledge is the use of, for example, unstructured or in-depth interviews, narrative research or focus groups. Service users 'bear witness' to each other's stories in what can be a powerful and empowering process (Hutchinson and Lovell, 2013; Faulkner et al, 2008; Anderson, 2016).

Qualitative methods may help us to hear the experiences and views of service users. This is certainly the approach that I have taken throughout my work (Faulkner and Layzell, 2000; Faulkner et al, 2008). However, qualitative methods alone may not be the answer. Used in the 'wrong' way (with the paradigm and the power inequalities unchanged and with people's stories reinterpreted inappropriately), qualitative methods can be just as disempowering as any other research method. Church (2013) challenges our use of narratives in qualitative research if we use and interpret them within the existing dominant (biomedical and positivist) paradigms. This is often done by the use of case studies where individual stories are re-told and re-interpreted by others in another form of silencing (Morgan et al, 2016). Costa et al (2012) similarly voice a radical challenge to what they refer to as the 'pornographic' use of people's stories. All of these authors (Church, 2013; Morgan et al, 2016; Costa et al, 2012) are calling for service users and survivors to take back control of their/our stories and to make our own interpretations about what our stories say, rather than falling in with the dominant paradigms of illness and recovery.

1.3.1 USER-CONTROLLED RESEARCH

The key piece of work to shed light on 'user-controlled research' was that undertaken by Turner and Beresford (2005), funded by the organisation INVOLVE (www.invo.org.uk). In defining it, they align user-controlled research with both survivor research and emancipatory disability research. In a later scoping review for the NIHR School for Social Care Research, Beresford and Croft (2012) refer to user controlled research as 'research that is actively initiated, controlled, directed and managed by service users and their organisations, exploring subjects and questions that concern them' (p.i).

At the heart of user-controlled research is that service users hold the control of the research, but it is also allied with the notion of empowerment or liberation of service users and disabled people inherent in emancipatory research. In this sense, survivor research might be the mental health sibling of user-controlled research. Report 3 in this thesis 'Changing Our Worlds' brings together seven examples of user-controlled research with the aim of learning more about what defines it and differentiates it from user involvement.

Language is fluid and changes over time and across disciplines. When we conceived of Report 1 'Strategies for Living' in 2000 as 'user-led research' we also meant that we held the majority control of that research. However, it was based within a non-user led organisation and hence certain financial and administrative aspects of the project were not entirely under our control. Turner and Beresford (2005) did not attribute much legitimacy to the term 'user-led', describing it as 'vague and ambiguous'. I would suggest that it is the first cousin of user-controlled research; as with any of these terms it is important to define them within the context in which they are currently being used.

1.3.2 USER INVOLVEMENT IN RESEARCH

In contrast to survivor research, the 'involvement' of service users in research generally led by clinical academics has become commonplace in the UK over the last two decades, hence attracting more funding and support than is ever likely to be available to survivor research. Indeed, in some areas, the involvement of service users, patients and carers (or 'members of the public' as they are often termed in this context) in health and social care research has become a criterion for funding. The National Institute for Health Research (NIHR) asks applicants to describe how they have involved the public in the design and planning of their

study as well as their plans for further involvement throughout the research; if they have not involved members of the public, they are asked to explain why (INVOLVE, 2012). Applicants are also asked to provide details of the budget they have allocated for public involvement in their research. Responses to these questions will influence funding decisions, although it is not clear to what extent. A commitment to public involvement in research is referred to in the Government's White Paper *Equity and Excellence: Liberating the NHS* (Dept of Health, 2010) and in the more recent report to the Department of Health *Going the Extra Mile* (NIHR, 2015).

The organisation INVOLVE, funded by the NIHR to support public involvement in NHS, public health and social care research, envisages a continuum of involvement, from consultation through collaboration to control by service users (members of the public). In reality, the continuum is probably quite skewed towards consultation and rather wobbly. Sweeney and Morgan (2009) talk of four levels of involvement: consultation, contribution, collaboration and control, but even this masks the potential for variation in form and inequalities at each level.

The language of involvement is in itself problematic; it implies that service users are involved in something initiated by others, and this is indeed often the case. As has been documented by many service user/survivor researchers (Russo, 2012; Beresford, 2005; Faulkner, 2004b), involvement in (clinical/academic) research brings with it many profound challenges. Not the least of these concerns the lack of authority to challenge the paradigm within which the research is constructed or the methods chosen for its implementation. As Turner and Beresford (2005) point out, user involvement in research embodies inequalities of power which work to the disadvantage of service users. Service users, patients or carers are often 'involved' at some point in the process too late to influence or challenge such fundamental assumptions which are laid down at the start. There is rarely funding available within the current structures to enable service users to become involved in the design of the research before it reaches the funding stage, at which point ethical approval may have already been gained and changes to the proposed research are more difficult to make.

Ultimately, academia remains the centre of power and positivist methodologies exert disproportionate levels of influence (Fisher and Freshwater, 2014). The question arises as to

whether public involvement in research is being deployed as a 'discourse of tolerance' (Fisher and Freshwater, 2014, p.201) acting to incorporate and neutralise challenges to the status quo. Stickley (2006) suggests: 'For as long as service users continue to be *involved* (in the historical sense of involvement), they reinforce the power of the dominant discourse' (p.576). All of this means that the experiential knowledge of service users and survivors can remain marginalised in research that involves them as advisers, co-researchers and interviewers (Russo, 2012). It also entails compromise, as is explored in this thesis in relation to Report 2, Papers 5 and 6.

1.3.3 RESEARCH IN CONTEXT

As pointed out by Turner and Beresford (2005), some of the largest 'user controlled' research projects to date have been based in voluntary sector organisations not controlled by service users. Whilst they did not explore this issue further, there is little doubt that the context in which research takes place matters – and it matters for the research represented in this thesis. The voluntary and academic sectors occupy different positions both culturally and politically. Academic research occupies a position of greater power and has access to larger sources of funding; it is also operating within a regulatory and funding framework that places constraints on academic researchers. The research undertaken by academic institutions and voluntary sector organisations may have overlapping values and goals, and they may work well in partnership on occasions, but there will also be significant differences. For example, voluntary sector research might be targeted at making a case for change (in services or attitudes) whereas academic research may be aimed at accumulating knowledge in a specialist area, motivated by obtaining research grants and achieving publications in peer-reviewed journals.

Barnes (2003) points out that the majority of UK research projects taking place in the early 21st century focusing on disability and related issues have been funded by charitable agencies and trusts such as the Joseph Rowntree Foundation (JRF) and National Lottery's Community Fund. 'Both these organisations prioritise user-led initiatives and concerns over those of the academy and professional researchers' (Barnes, 2003, p.6). Voluntary sector organisations tend to value accessible accounts of research – accounts that can make an argument for change, perhaps, or to evaluate their services and present a case to funders – but do not tend to give the same emphasis to methodological detail that would be the case

in an academic text. Consequently, even if research has been undertaken with rigorous attention to the methods, this may not be recorded in the published account of the research. Similarly, research carried out in the voluntary sector may remain unpublished or be published locally, and not achieve (or be interested in) publication in peer-reviewed journals (see also Paper 4: Telford and Faulkner, 2004). This will make it harder to find in conventional literature search methods, and less likely to be accorded equivalent status by academic researchers.

Finally, user-led organisations occupy another different cultural and political context. As demonstrated in Report 3 (Faulkner, 2010) many user-controlled research projects take place within small user-led organisations because of the underlying emancipatory ethos. These research projects may be small but, through highlighting the issues or priorities of marginalised communities – issues often neglected in mainstream research, they are able to inform and empower individuals and their communities.

1.4 IDENTITY AND POWER

Identity and power are core underlying themes to this thesis. My identities as mental health service user and researcher have driven my work from the beginning, giving rise to the belief that research can be done differently and in a way that empowers and includes people rather than pathologising and objectifying them.

Narratives are one way in which we 'make sense of our lives, our identities and our worlds' (Morgan et al, 2016 p.82). It is important to acknowledge that identity is not simply or solely an individual concept; it is socially mediated, complex and changeable. Jones and Kelly (2015) talk of the 'inconvenient complications' of identity; they highlight, for example, the significant differences in background and experiences between different individuals who identify as 'mad', and the ways in which we can mask these differences to the detriment of our knowledge and understanding.

Identity is fluctuating and complicated; we may move in and out of some aspects of our identity where others remain fixed and some are visible to others (e.g. race, gender (to some extent) and some disabilities) whilst others remain invisible. Some aspects of identity are chosen, others are given and yet others develop over time. To identify as a 'mental

health service user' is an interesting combination of these as, for some people, it may be a fluctuating or transient identity whereas for others, it may remain fixed.

Some identities clearly carry more status and power than others within society, and that of 'mental patient' or 'mentally ill' carries with it little status or power and considerable social stigma. With a mental illness diagnosis comes the additional stigma and discrimination associated with what has been referred to as 'spoiled' identity (Goffman, 1963). For many people who have been diagnosed with a mental illness of some kind, life becomes an ongoing endeavour to resolve this issue or to salvage a repaired or different, renewed identity (Deegan, 1996b). Within the context of a recovery narrative, rediscovering a sense of identity and self-confidence may be the first step towards embarking on a recovery journey (Brown and Kandirikirira, 2007).

Some people are reluctant to accept 'mental patient' or 'service user' as an identity because of the stigma associated with it, and others embrace it as they develop a renewed view or version of what it means to them. If we are seen solely through the prism of 'mental illness', however, it can be harder for us to adopt or embody identities of (for example) parents, lovers, academics and researchers. So, one identity can eclipse another at different times and in different contexts.

1.4.1 IDENTITY AND INVOLVEMENT

In the context of 'involvement' work, whether it is research, activism or service improvement, we adopt a particular identity when we become the people who are involved in something: usually as service users, sometimes as patients or members of the public (in Patient and Public Involvement (PPI) activities). We adopt or accept an identity associated with our experience as (ex-)mental health service users. In doing so we can find that the power relations in the world at large are played out locally within our involvement domains. Despite the fact that we are invited to become involved because of our personal experience, there is no guarantee that the power relations associated with being 'mentally ill' will be acknowledged or addressed so that we can contribute on an equal basis. On top of this there will be other key aspects of our identity that will come with us as we enter our involvement work: for example, we may identify as members of racialised communities, as gay, disabled or working class, to name but a few.

Indeed, one of the dilemmas facing those of us engaged in involvement initiatives, is that the power relations existing in the world may be replicated in situations where we have no real power, potentially perpetuating our disempowerment (Hutchinson and Lovell, 2013; Trivedi, 2001; 2009; Kalathil, 2013). This is particularly true for service users from racialised communities, whose role and power in these situations will be mediated as much by the identities and differences between BME and white people as by professional and service user identities (Trivedi, 2009). Black service users may be just as marginalised within white service user involvement initiatives as they are in relation to professionals (Kalathil, 2013). The professionals with whom we are working have (usually) adopted or accepted an identity associated with their work role, but they may also occupy other, more powerful identities in relation to the disempowered 'mental patient', i.e. as (white, male, middle class) psychiatrist, mental health nurse, social worker (Faulkner, 2016).

'User involvement' is both a personal and a political enterprise: political in that we do want to change some aspect of the mental health world and personal in that we bring sometimes painful and sometimes humiliating aspects of our personal lives and experiences to bear on the activity we are involved in (Faulkner, 2004a; Faulkner, 2004b). Our identity as 'mental health service user' is based on our life experiences, whereas the identity of our involvement colleagues are likely to be primarily based on their work role and professional experience. Undoubtedly this affects both parties in different ways and does not always fit well with the activity or the workplace concerned. Those whose job it is to plan and run services or to conduct research may not be familiar with the entirety of experience that we might bring with us into an involvement enterprise. Sometimes they struggle with the emotionality that we bring with us into 'their' workplaces. Sometimes we struggle with their failure to acknowledge or understand this and end up feeling painfully exposed. Any anger or tears we express may be interpreted in relation to our mental illness diagnosis. Interestingly, talking of the converse situation, Pollard and Evans (2013) talk of the 'emotional work' involved for researchers working with service users in the research endeavour.

Trivedi (2009) describes being forcibly admitted to an acute ward at a time when she was 'involved' in work with her local mental health Trust. Not only was she shocked at how little had changed in mental health services after years of involvement, but:

'Even more shocking to me was how, on my admission, I suddenly seemed to switch from my role as self-determining, actively 'involved' and respected service user (whose voice was actively sought) to one of coerced, 'un-involved' and disrespected psychiatric patient (whose voice was actively ignored or dismissed as being part of my symptoms).' (Trivedi, 2009; p. 138)

For myself, there have been times when I have wanted the ground to open up beneath my feet - as in the occasion when I walked into a seminar where I was due to speak about my experiences of acute mental health care to find a psychiatrist in the audience who had once admitted me to hospital.

1.4.2 COMPLICATED IDENTITIES

As illustrated by Trivedi, above, some of us occupy different, potentially competing, identities at the same time: perhaps we are both researchers and service users, complicating the power dynamics as well as the ways in which we see ourselves and in which others see us. It is a dilemma that has been well described by service user researcher Diana Rose:

"Among the many ways that power manifests itself in medical research is when senior academics do not treat a service user as a research collaborator, and simply regard the person as somebody's (a potential?) patient. I have been in research meetings that suddenly felt like a ward round. One's user status may be used to undermine one's opinions, as it is held that a person cannot be both logical and mad. It is a difficult balance to strike—that having a diagnosis and experience of services is a qualification for the job and not a handicap. This is the reverse side of the value of a double identity, and I do not pretend to have resolved the issue" (Rose, 2003a, p.1).

Those of us who have acquired research skills may occupy a space somewhere in between the (non-service user) clinical academics and the service users who are the participants in the research. This can mean that we fall through a gap in between these two identities, or it can mean that we have something new to offer. Elsewhere (Faulkner, 2016), I have suggested that those of us who wear these two hats (researcher and service user) have a

particular responsibility to both uphold the value of service users as equal partners in the production of knowledge and the value of good quality research.

This means taking a political stance in relation to our dual identity/ies. As Rose (2014b) points out, it is not just a simple case of being a researcher who happens to have experience of using mental health services: it is about using 'their experience of being in receipt of services to inform their research practice from start to finish' (Rose, 2014b, p.154). This is important, because it begins to draw a line around who can legitimately call themselves a service user researcher or survivor researcher. I did not do this myself until I went through a period of transformation and a kind of 'coming out' period which in some ways paralleled coming out as lesbian in my twenties. My experience of using mental health services began when I was doing my degree, which I nevertheless completed successfully and went on to work as a researcher, largely placing my mental health experiences behind me. Some years later, I went on to renew my contact with mental health services in the 1990s as I turned 40. On this occasion, and as I travelled the 'Strategies for Living' journey with my colleagues, I revised my identity in relation to mental distress and mental health services and in relation to research. A kind of parallel journey is related by Kathryn Church (1995) in a frank account of her experiences in the book 'Forbidden Narratives'.

However, there is a dilemma here: some 'service user researchers' may be less prepared to adopt this identity as it can become fixed and unchangeable over time, particularly if your name is identified in relation to research publications. The dilemma may be related in part to your diagnosis (schizophrenia and personality disorder being subject to the greatest discrimination) and where you are in relation to your age and life or career. What happens if you want to move into different research or to lose or occlude the 'service user' identity at some point in the future? Rose (2014b) discusses this in relation to new and less politically identified researchers joining the Service User Research Enterprise (SURE) at King's College, London. Hutchinson and Lovell (2013) also point out the dangers of adopting a fixed identity through involvement work which, they suggest, can perpetuate and sustain the negative impact of the label through being seen solely in relation to our role and identity as 'service users'. Lewis (2013), writing about her research with service user groups in Scotland, critically examines the pitfalls of adopting the identity for involvement purposes. Indeed, she sees little to be gained from adopting the identity, describing the 'mental illness'

identity as 'stigmatising and all-defining' and 'impossible to positively assert' (Lewis, 2013, p. 92).

And yet, it must be possible to 'positively assert the identity' within certain contexts, or many of us would not do it. Activism involves doing just this. An edited collection of writings from over 40 psychiatric survivors (Burstow and Weitz, 1998) is referred to by Morgan et al (2016) as 'an assertion of the 'mad' identity by reclaiming and re-articulating that experience' (p.86). Rose (2003a) refers to the irony of a mental illness diagnosis being a required criterion for her job at SURE, after years of attempting to hide it. It is not simply a case of being prepared to take the risk, but of using the experience and the identity in order to work with and for people to challenge the dominance of psychiatry and of mainstream research paradigms and constructs. What drives many of us to embrace the identity is not just bad experiences of the system and the desire to make things better, but the powerful belief that psychiatry has got it wrong. At the core of embracing the identity lies the belief that there is value in experiential knowledge: without some people embracing the identity of survivor/service user/expert by experience, how would experiential knowledge be located and given any status within the academy?

Finally, there are other competing and compelling identities that influence us in our work and in our lives. This thesis is seen through the prism of a white, middle class, mad gay/lesbian identity, with considerable privilege as well as some disadvantages and sources of disempowerment and discrimination. Service users and survivors from racialised communities face greater discrimination and marginalisation; they are less likely to become 'involved' in the activities dominated by their white counterparts. Kalathil (2013) points out that the mainstream definition of involvement excludes 'a lot of the work that people were doing on the ground, within their communities' (Kalathil, 2013, p.128).

I do not claim to have an answer to these dilemmas, and find myself continually re-evaluating myself and my identity in relation to them. I am not using mental health services now, although I still remain on a small amount of medication; what can I call myself? Should I more accurately use the term 'survivor' or 'ex-service user'. The term 'survivor' implies a more political position in relation to the mental health system, but for some people it can alienate for different reasons. I frequently refer to myself as 'service user/survivor' in order

to cover all bases. In some ways, however, what I call myself does not matter as much as the position I am prepared to take in relation to the work that I do.

1.5 STANDPOINT THEORY

Mainstream mental health research is carried out (predominantly) from a clinical /professional perspective or standpoint (Jones and Brown, 2013). It assumes the professional 'gaze': the we who do the thinking and the writing are the (mainly white, male) rational professional researchers looking at, investigating, those who are mad, mentally ill and irrational (Rose, 2003a, 2014b). People with mental health problems are the subjects of that research and are objectified and pathologised as representatives of diagnoses or as users of a particular service. They do not have their own voices as individuals with complex lives; they do not have the chance to tell their story of how they came to be here and now and with these problems underlying this diagnosis: to give their own meanings and context to the story (Morgan et al, 2016).

For me, the interesting point comes when the mad come to take the position of the researcher and take the authority to assume that stance and take ownership of the knowledge. Rather akin to feminist theories addressing the 'male gaze' or black communities addressing the 'white gaze' in visual and literary arts (Kaplan, 1997), the 'we' becomes us instead of 'them'. For Kaplan and others, the 'gaze' is dominating and objectifying; it assumes that 'we' who adopt the gaze are white, male. Humphries et al (2000) explores the notion of locating the self in relation to our research in order to enable empathy with research participants and as 'a means of avoiding objectification through the research gaze' (Humphries et al, 2000; p. 14).

Some of the dilemmas this raises for academics striving to work ethically with social movements are discussed by Church (1995) and Cresswell and Spandler (2012). Church describes herself as 'a writer whose best stuff goes into email' (<http://www.ryerson.ca/disabilitystudies/for-faculty/index.html>). In refusing to play the academic game by aiming for peer-reviewed papers, and recording a journey through her own breakdown, she retains solidarity with psychiatric survivors but does not achieve academic progression. Cresswell and Spandler (2012), as academic non-survivors, advocate the position of 'engaged academic' taking a politico-ethical stance 'which seeks to transform

and democratise the psychopolitical field' (p.13). All of these writers are struggling with the pull of the academic gaze to objectify individuals and social movements.

The difficulty of this challenge comes to the fore when writing about research, particularly for peer-reviewed journals where it is assumed that the authors will refer to people with mental health problems as 'they' and 'them' where we would wish to refer to 'them' as 'we' and 'us'. Collins (2009) talks of rejecting the distancing pronouns 'they' and 'their' when she talks of the contribution that Black women intellectuals can make to Black women's group standpoint by using their experiences as 'situated knowers' (p.19).

Standpoint theory addresses these issues in a useful way (Rose, 2014b). Standpoint theory (originally feminist standpoint theory (Harding, 1993)) involves de-centering the production of knowledge, challenging existing (androcentric) paradigms. A standpoint is more than simply a perspective: 'a person's standpoint is a privileged view made possible (albeit far from automatically given) by their location' (Burstow, 2015, p.18). For Sandra Harding (1993), standpoint theory proposes starting the process of inquiry from an '*explicitly social location*': from the lived experience of those persons who have traditionally been excluded from knowledge production. Usually, in the case of feminist standpoint theory, this is women reclaiming the scientific 'gaze', as it were, from men. But the theory has been extended to other marginalised groups and communities, seeking to produce what Harding refers to as 'a stronger objectivity': the idea that marginalised groups have a more complete knowledge because they have access to the mainstream discourse as well as their own (Harding, 1993). This has particular relevance in relation to the knowledge discussed in this thesis.

CHAPTER TWO: THE PUBLICATIONS

In this chapter, I take each publication in turn and outline the context for the research, the research methods used and the key findings. In some instances two or three publications are taken together where they relate to one piece of research. The publications are relatively diverse in terms of theme and content; the process and methods of conducting the research constitute a major part of their contribution to the knowledge surrounding mental distress.

TABLE 2.1 PUBLICATIONS AS ADDRESSED IN THIS CHAPTER

Report/ Paper	Title	Approach taken	Chapter section
Report 1.	'Strategies for living: a report of user-led research into people's strategies for living with mental distress	<ul style="list-style-type: none"> Qualitative: depth interviews 	2.1
Report 2.	Learning the Lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder.	<ul style="list-style-type: none"> Qualitative: depth interviews Part of a large mixed methods evaluation 	2.2
Report 3.	Changing Our Worlds: Examples of user-controlled research in action	<ul style="list-style-type: none"> Multiple case studies 	2.3
Paper 4.	Learning about service user involvement in mental health research	<ul style="list-style-type: none"> Review paper 	2.4
Paper 5.	Dedicated personality disorder services: A qualitative analysis of service structure and treatment process	<ul style="list-style-type: none"> Qualitative: depth interviews Part of a large mixed methods evaluation 	2.2
Paper 6.	Learning the Lessons Together	<ul style="list-style-type: none"> Reflections on the process of involvement 	2.2
Paper 7.	A helping hand: taking peer support into the 21st century	<ul style="list-style-type: none"> Qualitative: focus groups 	2.5
Paper 8.	A long and honourable history	<ul style="list-style-type: none"> Qualitative: focus groups 	2.5
Paper 9.	Service users' views of risk	<ul style="list-style-type: none"> Qualitative: depth interviews and focus group 	2.6
Paper 10.	Institutional Conflict: the state of play in adult acute psychiatric wards	<ul style="list-style-type: none"> Review paper, personal reflection 	2.7

2.1 STRATEGIES FOR LIVING: A REPORT OF USER-LED RESEARCH INTO PEOPLE'S STRATEGIES FOR LIVING WITH MENTAL DISTRESS (FAULKNER AND LAYZELL, 2000), LONDON: THE MENTAL HEALTH FOUNDATION.

2.1.1 *THE CONTEXT FOR THE RESEARCH*

This study was based within a voluntary sector organisation (the Mental Health Foundation) and funded by the Big Lottery. It followed a survey of 400 people's experiences of treatments and therapies entitled 'Knowing Our Own Minds' (Faulkner, 1997). At the time of the survey the Mental Health Foundation was known as a funder of medical research in the field of mental health and of a limited number of community projects. The Lottery was introduced as a new funder on the research scene, prioritising the voluntary sector, at the same time as the Foundation was undergoing significant change. The CEO and senior management team were keen to redress the balance of the organisation and fund research that focused on the priorities of people with direct experience of mental health problems.

This study was identified as 'user-led' in that all of the researchers and interviewers on the project had lived experience of mental health problems; however, it was based within a non-user controlled organisation so the financial management of the project was with non-service users. The value of being based within a substantial voluntary organisation with fundraising resources cannot be overestimated, since it was these resources and people that enabled the project to happen. As a team of service users and survivors, we designed and carried out the research; I managed the project, and took the lead in analysing and writing up the report with co-author Sarah Layzell.

This study laid the groundwork for much of the work that follows in this thesis by foregrounding the service user perspective: ensuring that the research questions were designed and delivered by mental health service users as researchers, and establishing service users as the 'knowers' of research-produced knowledge.

2.1.2 *METHODS*

This was a large-scale qualitative investigation of people's experiences of mental health problems and their different ways of managing, coping or dealing with them. The study formed part of a significant proposal to the Big Lottery, which also included training and

capacity-building with service users to carry out small-scale research projects. This study followed up a previous survey ('Knowing Our Own Minds'; Faulkner, 1997) with the aim of understanding some of the findings in more depth. This, together with the aim of exploring an area of knowledge previously unexplored, formed the rationale for choosing qualitative methods. In addition, as service users and researchers, we were concerned to ensure that people felt able to tell their stories with limited structure imposed from us as interviewers; consequently an unstructured approach with the minimal guidance of a topic guide was deemed appropriate.

A sample of 76 people were originally selected to reflect a range of backgrounds and experiences, based on information gathered in the 'Knowing Our Own Minds' survey. The following characteristics were used to design a purposive sample: experience of alternative/complementary therapies; gender; ethnic origin; geographical location; diagnosis.

We recruited participants through a combination of methods. Some were followed up from the 'Knowing our own Minds' survey; others were contacted through voluntary sector projects and services, service user and self-help groups, day centres and drop-ins. We aimed for an almost equal (40:35) ratio of women to men and for representation across six geographical regions of the UK. We aimed for a total of 15 South Asian and 15 Black African Caribbean people, in order to represent their views adequately. We targeted a subset of BME voluntary sector projects to recruit South Asian and Black African/African Caribbean people. We were also required by the funder to recruit a substantial proportion of people with 'severe mental health problems'. Since this is a controversial concept among service user and survivor groups, we decided (in discussion with the Advisory Group) to aim for an equal number of people with psychotic and non-psychotic diagnoses.

The final sample of 71 people largely satisfied our sampling targets, although there were substantially more women than men (42:29) and fewer African Caribbean people than we aimed for (nine).

Ethical approval was not obtained for this research; the participants were recruited through open channels and so it did not require ethical approval at the time. If the study were to be carried out today, ethical approval would be sought in order to ensure that both researchers

and participants were covered and protected by a transparent ethical process. Nevertheless, an ethical approach was undertaken: participants were all contacted in advance with details of the research and of the person who would be interviewing them. On the day, they were again given an information sheet about the project, and invited to give their informed consent through signing a consent form. It was made clear to participants, both in written and verbal information, that the study was being led and carried out by people with direct experience of mental distress.

We engaged five service user/survivor interviewers to the research team, with the aim of reducing the power imbalance between researcher and researched (Beresford, 2003; Beresford, 2005). In undertaking this research, we were conscious of the over-representation of some BME communities within mental health services and, conversely, the under-representation of others for whom accessing mental health services presents both barriers and ambiguities (Fernando and Keating, 2009; Thomas, 2014; Kalathil, 2011b). We employed one Black African Caribbean interviewer and one South Asian interviewer to enable a further reduction in the power relations between interviewer and interviewee to take place for participants from these communities (Truman, 2000). We endeavoured to match interviewer and interviewee by gender and race where possible. This practice has often been recommended in relation to building rapport between interviewer and interviewee in social research and encouraging more open and honest responses (Gray, 2014; Breakwell et al, 2006; Crano et al, 2015), but it can also usefully establish credibility with marginalised communities (Truman, 2000). It has been shown that if the interview topic has particular relevance to race, interviewees are more likely to respond openly to someone of the same or similar race as themselves (Gubrium and Holstein, 2001; Crano et al, 2015).

The researchers and interviewers all received training in depth (unstructured) interviewing from Jane Ritchie and Kit Ward of Social and Community Planning Research (SCPR) - now the National Centre for Social Research (NatCen).

We used an unstructured approach to the interviews with a topic guide covering the range of possible supports, therapies and treatments that we thought people might find helpful, partly based on the 'Knowing Our Own Minds' survey. The research team developed the

topic guide together with the advice and support of the project Advisory Group, whose members were drawn from mental health service user-led organisations; consequently, the topic guide was grounded in service user/survivor knowledge. Interviews were tape-recorded for full transcription and we used framework analysis to analyse the data (Ritchie and Spencer, 1994). The analysis was carried out by the two authors in consultation with the interviewers. All of the interviews were entered on the qualitative data analysis programme NUDIST (Richards and Richards, 1990) which we used to organise the data into broad categories. An index was devised in discussion with the interviewers and based upon reading a sample of interviews to ensure that it was grounded in the data. This was then used to code the interview transcripts. From this coding a series of matrices were drawn up based on the themes arising. During the analysis we referred constantly to the demographic information to see how this related to the overall themes.

My role in this piece of work was as project manager for the research and I took the lead role in the analysis and report writing. I was also actively involved in putting the original proposal together for the Lottery, having previously carried out the survey 'Knowing Our Own Minds' (Faulkner, 1997).

2.1.3 KEY FINDINGS

The key findings are described at two levels: the strategies or sources of support identified by participants, and the themes underlying those strategies: the motivations that were played out through different strategies for different people. In one of our early discussions as a group looking at the findings, we wondered if a key finding of the study might be that 'everyone is different'. Although some themes emerged across the interviews, we were initially impressed by the complexity and variety of ways in which people had found to live with and survive mental distress. Of major significance was the role of relationships. This is not a surprising finding, but the strength of this alongside the lesser focus given to services and medical treatments, did present a very different picture of the lives of people living with mental distress to that often presented by mainstream mental health research. Interesting and unusual things emerged too, such as the role of spirituality for some people (with or without religion) and the role of fun or pleasure, which we are often at risk of forgetting. The role of the voluntary sector was particularly significant for black and minority ethnic

service users, many of whom found acceptance and a sense of belonging in BME projects and services set up to by and for communities.

TABLE 2.2 KEY FINDINGS FROM STRATEGIES FOR LIVING

1 Most helpful strategies and sources of support	
Relationships with others	<ul style="list-style-type: none"> • Friends • Other service users/people with similar problems • Mental health professionals • Counsellors/therapists • People encountered in day centres, drop-ins, voluntary sector projects
Personal strategies	<ul style="list-style-type: none"> • Peace of mind • Thinking positively • Taking control
Medication	
Physical exercise	
Religious and spiritual beliefs	
Other activities	<ul style="list-style-type: none"> • Hobbies and interests • Information • Home • Creative expression

2 Underlying themes
Acceptance
Shared experience... shared identity
Emotional support... 'being there'
A reason for living
Finding meaning... and purpose
Peace of mind... and relaxation
Taking control... having choices
Security ... and safety
Pleasure and fun

Reflections by the service user researchers and interviewers (Faulkner and Layzell, 2000; Chapter 6) began to develop our understanding, both of the findings and of user-led or survivor research in mental health. We explored our shared understanding of what it means to experience both distress and discrimination and to use this knowledge to carry out research that could be meaningful to the wider community of people experiencing distress, service users and survivors.

2.2 LEARNING THE LESSONS: EVALUATION OF COMMUNITY-BASED SERVICES FOR PEOPLE WITH A DIAGNOSIS OF PERSONALITY DISORDER

- **Report 2:** Crawford, M et al* (2007) Learning the lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder. National Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health. *18 authors listed.
- **Paper 5:** Price K, Gillespie S, Rutter D, Dhillon K, Gibson S, Faulkner A, Weaver T, Crawford MJ. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health* 18, 467–475
- **Paper 6:** Faulkner, A., Gillespie, S., Imlack, S., Dhillon, K. and Crawford, M. (2008) Learning the Lessons Together. *Mental Health Today*, February, 24-26.

2.2.1 THE CONTEXT FOR THE RESEARCH

These three publications relate to a large multi-methods evaluation of 11 community-based services for people with a diagnosis of personality disorder, led by Professor Mike Crawford at Imperial College, University of London and funded by the National Institute of Health Research (NIHR). The aims of the research were to evaluate these specialist services and learn the lessons from their initial phase of development. In order to achieve these aims the research set out to: describe the organisational form, activity and function of the 11 pilot services; compare aims and objectives of services with those they actually deliver; measure health, social function and service utilisation among a sample of people referred to these services; and identify organisational, therapeutic and other factors that service users and providers believe result in high quality care for people with a diagnosis of personality disorder.

The research was organised into four modules:

1. An exploration of the demographic and clinical characteristics of people who have been referred to and taken on by the pilot sites;
2. In-depth interviews with service providers (managers and front-line staff at each of the services), referrers and commissioners;
3. In-depth interviews and focus groups with service users who were currently using the pilot PD services, service users who have previously used the pilot PD services, and carers of people who are using/had been using the pilot PD services;
4. A national survey aimed at finding out how service users, service providers and expert authors believed services for people with PD are best organised.

Module 3 was undertaken by the Mental Health Foundation as a 'user-led' module within a research project led by clinical academic researchers. Consequently, this is technically 'user involvement in research': the agenda for the research was set by the NIHR and designed by a team led by clinical academics. Nevertheless, Module 3 was established as a self-contained user-led module based within the voluntary sector. As such, this is an unusual form of user involvement in research and does not fit easily into the continuum described in section 1.3.2.

Working with a team of two researchers based at the Mental Health Foundation, I provided the training and support to the service user interviewers, and then coordinated the analysis and the report writing (section 4.3 in Report 2, pp96-123). This work demonstrated both the potential for service user involvement in the research process (including the analysis and report-writing), and the value of doing so for the overall quality of the study. This kind of approach requires resources in terms of time, money and people; we were fortunate to be able to carry out such a large scale piece of user-led research and to have the resources to do it well. In the author's experience, this is a rare example of such extensive involvement of service user researchers in the research process. It was unusual in that the module was able to be a self-contained user-led project within a large-scale academic research study.

2.2.2 METHODS

The overall study was a mixed methods evaluation, employing quantitative and qualitative methods for the different elements. This consisted of: an organisational evaluation

examining the context, form, and function, of the 11 pilot services; a cohort study examining demographic and clinical characteristics of a sample of those referred to the services; a user-led qualitative evaluation of service users' and carers' views and experiences; and a Delphi study examining the level of consensus among expert authors, service users and providers about key aspects of the organisation and delivery of dedicated services for people with PD. Ethical approval was sought and obtained for all parts of the project, and as the sites covered a wide geographical area, we needed to approach several Research Ethics Committees.

The aim of Module 3 was to explore the experiences of people using the pilot community services and their carers, with a view to identifying what influenced their perceptions of service quality and outcomes, as well as factors that affected their decisions to engage with or end contact with services. The services were new and innovative, which highlighted the need for qualitative methods to hear people's views and experiences of the services without too much imposed structure. It was important to allow people to speak and for researchers to listen to their experiences, particularly in circumstances where some service users might be experiencing current distress.

Eleven service user research interviewers were recruited and trained in qualitative research and interviewing skills by the author. Telephone and face-to-face peer support and research supervision were provided throughout the period of data collection by myself and other members of the research team. In addition, a member of staff was available within each service should the interviewers need to speak to someone or to de-brief after an interview.

A purposive sampling strategy was used to recruit seven to ten current service users, up to three carers and three past service users at each site for individual interviews. Within these categories a secondary list of sampling criteria was used to ensure a mix of gender, ages, component of service used and length of contact with the service which was broadly similar to the mix of service users in contact with each service. Interview schedules for interviews with service users and carers were developed on the basis of a literature review, the views of service user researchers and feedback from members of the Project Advisory Group. The topic guide consisted of a series of open-ended questions covering the following themes: information received, deciding to try the service, the process of coming in, assessments and

diagnosis, support received, contact and relationship with staff, relationships with other service users, service user involvement, outcomes and ideas for improvements.

The majority of the participants were interviewed by pairs of interviewers due to the sensitive nature of the services and the potential distress of both participants and interviewers. The interviews were tape-recorded and transcribed verbatim where possible. Where participants did not consent to their interviews being recorded, researchers took comprehensive field notes by hand, using verbatim notes where possible which were checked back with participants for accuracy.

Data analysis & validation

Seven of the service user researchers were trained alongside the core research team in Ritchie and Spencer's Framework approach to qualitative analysis (Ritchie and Spencer, 1994). The qualitative data were analysed and the findings validated through a process involving group and individual meetings with members of the validation team comprising the three Mental Health Foundation lead researchers (including the author). Validation focused on credibility and auditability tracking the data from raw data, through coding, charting and summarisation stages. Through this process the initial thematic framework was amended with emergent themes from analyses across the 11 sites. Individual site summaries were produced detailing issues arising from the service user journey through the service, and learning points were extracted from these summaries for inclusion in relevant sections of the broader research report.

2.2.3 FINDINGS FROM 'LEARNING THE LESSONS'

The findings from this study fall into two categories: the content findings from the interviews with service users and carers, and the process findings from the service user researchers. An important context for the findings is that these services were pilot services and many were therapeutic communities or based along similarly therapeutic lines. The findings below are included in full in the main report (Report 2).

Paper 5 addresses the full complement of the qualitative data gathered from the research, summarising the findings concerning the service structure of the 11 services, the nature of the treatment and support on offer, and the experiences of service users, carers and staff. The author's contribution to this paper was to ensure the accuracy of the findings relating to

Module 3 (service user and carer experiences) and contribute to the discussion. The paper was led by Katy Price, one of the academic researchers based at Imperial College, London.

Paper 6 was led by the author and constitutes the report of reflections carried out jointly by the Mental Health Foundation research team and service user researchers who carried out Module 3. Several of the researchers and interviewers had received a diagnosis of personality disorder at some point in their lives and so the research was personal to them. We needed to reflect on that and to share our experiences of carrying out this significant and challenging piece of research together.

CONTENT FINDINGS

The team were successful in interviewing – or including in focus groups – a total of 133 people: 108 current service users, 15 ex-service users and ten carers. There were a great many complex findings arising from the analysis of these interviews (Section 4.3 in Crawford et al, 2007). They covered the following issues:

- Assessment procedures for the services were found to be lengthy and sometimes traumatic. Many people approached the services in both desperation and hope, having been rejected by previous mainstream services as a result of their diagnosis.
- There were very mixed views, experiences and feelings about receiving a diagnosis of personality disorder, often influenced by the (negative) implications it held for accessing services, but also for the sense it conveyed of having a damaged personality or self/identity.
- These pilot services were experienced as being very different to mainstream mental health services; this highlighted the need for clear and accessible information to be provided about them, both to potential service users and to local professionals responsible for signposting or gate-keeping.
- Service users experienced a lack of flexibility within certain services about the model and approach undertaken. Rules were often rigid but implicit, making it difficult for people to understand or appreciate what was going on. Conversely, accessibility and flexibility, when encountered within services, were appreciated by service users;
- Some services were valued for giving service users a sense of belonging or family;
- Good, accessible crisis or out of hours support was a valued part of some services.

- Therapeutic boundaries and rules were sometimes unclear and inconsistently applied; people felt that a degree of flexibility or open negotiation about rules could increase people's understanding and appreciation of them.
- Peer support was a highly valued element of many of these services; however, where peer support was the core of a service, there was not always adequate support in place to sustain it.
- In one or two of the services difficulties arose between cliques that had formed; the opportunity to raise these issues with staff was not always easily available.

PROCESS FINDINGS: PAPER 6

As a team, we met at regular intervals to support each other and to reflect upon our experiences of working on this project in addition to training together at the start. The results of this process formed the basis of Paper 6. The learning from this project discussed by group members included:

- Capacity-building, learning new skills – e.g. qualitative analysis;
- Discovering that we could overcome our own vulnerability with support, and do this kind of work.
- Having our prejudices challenged – both about the diagnosis and its treatment.
- The value of co-working and peer support, alongside the need to care for ourselves and to be aware of our own limits.
- A sense of hope from encountering positive services which were making a real difference to people who are often written off by services.
- Contributing to the body of knowledge of 'user involvement in research', particularly the value of being involved in the analysis as well as the interviewing; we felt that this both added to our own learning and ensured an extra level of validity to the findings.
- Challenging stereotypes about service users and what they/we can and cannot do; breaking down barriers between researchers and service users.

There were also some significant challenges, including overcoming the practical barriers to involvement - such as ethical approval, R&D permission and, for some researchers, the need to undergo occupational health checks which meant disclosing their psychiatric history.

Another challenge involved the therapeutic nature of the services and (possibly) an over-protective attitude towards their service users. Staff in some services were unwilling to permit research focus groups and in other services, reluctant for their service users to be interviewed individually.

A serious challenge to the team was the need to negotiate our own varying mental health and levels of distress in the context of a demanding piece of work. As a team, we reflected on our ability to manage this through formal and informal peer support, combined with a flexible approach that meant that we could cover for each other at times and drop in and out of the project if necessary. Being able to interview in pairs was valuable in situations where an interview became difficult or distressing.

2.3 FAULKNER, A. (2010) CHANGING OUR WORLDS: EXAMPLES OF USER-CONTROLLED RESEARCH IN ACTION. EASTLEIGH: INVOLVE

2.3.1 *THE CONTEXT FOR THE RESEARCH*

This study was commissioned by INVOLVE, the national advisory group for the NIHR on public involvement in research. Interestingly, the advisory group had identified the need to better understand ‘user-controlled’ research a couple of years before this study was commissioned, giving rise to the report ‘User Controlled Research: its meanings and potential’ (Turner and Beresford, 2005). At the time, INVOLVE was using a continuum to describe public involvement in research, from consultation at one end through collaboration and involvement, to control at the other end (Hanley et al, 2004). Whilst they were (and are) primarily concerned with the middle ground in this continuum, they also expressed the need to understand the full landscape.

The current study followed on from the Turner and Beresford (2005) report, in identifying and describing examples of user-controlled research, so as to better describe some of the factors and features that they have in common. The report describes seven examples of user-controlled research, each in different areas of health and social care, and adopting different research methods. The report illustrates some of the key themes and issues that (I will argue) can only be effectively explored through user-controlled research: issues such as empowerment, identity and capacity-building. These projects are small and hence

somewhat limited in the extent to which their findings could be generalised. However, they demonstrate the impact that small user-controlled research projects can make on the disabled people and service users involved and on their immediate or wider communities.

2.3.2 METHODS USED

The methods used in this study follow multiple case study methodology (Hyett et al, 2014) in that a number of cases (in this case of 'user-controlled research') are selected for parallel comparison of common themes. This study was designed to complement a previous mapping exercise, also commissioned by INVOLVE, which identified 45 examples of user-controlled research across the health and social care research spectrum. These projects formed the pool from which the seven examples were selected for this more detailed exploration.

A structured process was followed to select the seven projects from the initial pool in order to check that they fulfilled the criteria for 'user-controlled' research. Each project was reviewed by two people from the Advisory Group, using the information submitted to the mapping project. Each project was checked against four criteria:

1. The projects were user-controlled (Turner and Beresford, 2005).
2. The projects were research (as against service development work or consultations).
3. The topic was relevant to health, public health and social care research.
4. The project was ongoing or completed within the past two years.

Where there was agreement between the two reviewers that all four criteria were met, the projects were added to the list for possible selection for the case studies. This led to a short-list of 19 projects which fell into seven themes: learning difficulties; mental health; young people; general health; disabled people; lesbian, gay, bisexual and transgendered people; and general user involvement. Across these themes the projects were then listed in rank order to achieve greatest diversity across the range of other factors including funding source, aspects of user-control and any distinctive features of the projects. The project at the top of the ranked list for each theme was approached successfully.

The second stage was to formulate a topic guide: a preliminary list of questions was amended following discussion with the advisory group and evolved as interviews progressed. Interviews did not necessarily follow this list rigidly however; they were regarded as semi-structured conversations and often diverged to discuss interesting tangential issues.

Site visits and small group or individual interviews were undertaken with six of the projects; telephone interviews alone took place with the seventh. Supplementary telephone interviews or email exchanges were undertaken where key informants were unable to be present at a site visit. For example, the project undertaken by Vision Sense was commissioned by the PCT (Primary Care Trust) so a telephone interview was carried out with the relevant commissioner. Where possible, interviews were recorded and transcribed for subsequent analysis, for which framework analysis was employed. Interviews conducted face-to-face were filmed for the accompanying DVD.

It was not possible to contact all of the people involved in the production of all of these projects. Some people did not respond to approaches made; others were no longer involved with or employed by the original organisation and proved impossible to find. There is always the possibility that the people who did not respond may have held different views about the projects than those who did.

We also used copies of each project's reports and the internet as sources of additional information. In some cases, it was possible to trace references to the projects and their reports online through third parties (e.g. the Department of Health in the case of the Rainbow Ripples report; the London Borough of Tower Hamlets for DITO's (Disability Information Training Opportunity) Disability Hate Crime research, and so on). The first draft of each case study was sent back to the project participants to check for accuracy; amendments were made accordingly. Participants also had the opportunity to review and comment on the full report prior to publication.

The seven examples are presented separately in the report; the presentation of the examples varies a little in line with the individuality of the projects so not all of the sub-headings used are consistent. After the seven examples, a commentary on the common themes and issues arising from the examples is presented.

2.3.3 FINDINGS FROM CHANGING OUR WORLDS

Despite originating from different groups and from different experiences of health or disability, the seven cases gave rise to some strong common themes. All of the projects originated out of a strong commitment to change or improve the lives of their community of service users or disabled people, whether directly or indirectly, locally or nationally.

Findings from the projects suggest that user-controlled research often arises from a sense of frustration with mainstream research and services that overlook or exclude marginalised groups. Frustrated by the failure of mainstream research to capture their needs or research the things they thought important, these groups or organisations found ways of doing the research themselves. The projects adopted different research approaches, levels of control of the research and sources of funding. However, they discussed similar benefits and challenges. The benefits of having undertaken user-controlled research identified by the participants fell into the following themes:

- Making change happen
- Access and trust
- Improved research quality
- Empowerment
- Credibility

The challenges encountered by the projects fell into the following themes:

- Resources
- Discrimination
- Dilemmas surrounding identity and power
- Distress

One of the themes explored further in this thesis is that of identity and power. Having control over the research did not necessarily mean that issues of control and power were unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. It could lead to an acute awareness on the part of the researcher about their role and the power they had newly adopted in relation to their interviewees. They were no longer entirely 'equal'. In

addition, this shared identity could at times lead to distress on the part of researchers who shared difficult experiences with the people they interviewed.

Nearly all of the researchers interviewed had some experience of discrimination to report in relation to the research process. One disabled man was verbally abused as he left an interview, and the researchers involved in the lesbian and gay research in Leeds also encountered discrimination during the course of the study.

Nevertheless, nearly all of the researchers talked of a sense of empowerment and the value of working with their community or group to bring about change. This issue of change is central to the ethos of user-controlled and emancipatory research (Beresford and Wallcraft, 1997). Nearly all of these projects achieved some degree of change within a local or national context. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development. Some of the service users who became researchers in these projects talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research. Many of the projects resulted in tangible outputs which aimed to extend their impact to their wider community of disabled people or service users. Examples of these include: training packs, information packs and a dedicated website, a training programme, DVDs and an improved pathway through mental health services.

2.4 TELFORD, R. AND FAULKNER, A. (2004) LEARNING ABOUT SERVICE USER INVOLVEMENT IN MENTAL HEALTH RESEARCH. *JOURNAL OF MENTAL HEALTH*. VOLUME 13, NUMBER 6, DECEMBER 2004 , PP. 549-559(11)

2.4.1 THE CONTEXT FOR THE RESEARCH

This paper was written in collaboration between the two authors and was led by the lead author, Rosemary Telford. The initiative for the paper came from the authors' differing and complementary experience of involvement in mental health research: Rosemary from a clinical academic perspective (with a significant interest in user involvement) and me from a service user/survivor perspective. There was no funding for this paper; it was undertaken out of interest in the subject and concern to record the learning that was building up in the

field at the time. Both authors were members of the INVOLVE Advisory Group at the time of writing the article. In this paper, my contribution was to present and discuss the learning from the 'grey' or alternative literature (often arising from the voluntary sector) and to give examples from practice.

2.4.2 METHODS

This paper undertook to review the learning about service user involvement in mental health research to date, building on the earlier paper of Faulkner and Thomas (2002). The aims of this paper were to explore aspects of service user involvement in mental health research. We were concerned to determine the level of understanding about it, to what extent it seemed to be taking place, the motives and incentives behind user involvement in research, and the barriers to involvement from both service user and researcher perspectives. Both peer-reviewed and 'grey' literature was examined to explore the extent of service user involvement in mental health research, and ways in which service users were carrying out research.

The paper outlines UK policy developments in what has been variously termed 'consumer involvement', 'public involvement', 'patient and public involvement', and 'user (and/or carer) involvement' in research. Language and meaning in relation to these terms is analysed. The authors then discuss the motives and incentives to involvement from both service user and professional /academic perspectives and the barriers to involvement. A number of practical examples of user involvement in mental health research are then given, including Strategies for Living (see Report 1), and the Service User Research Enterprise at the Institute of Psychiatry, King's College London.

2.4.3 FINDINGS

Incentives identified by the authors for service users getting involved included: frustration with clinical academic research; promoting the value of expertise by experience; seeking change and improvements; asking different questions and getting different answers; challenging models of understanding; and developing skills, confidence and empowerment. For researchers, the incentives included: pragmatic considerations associated with funding criteria and moral and political motives to include people whose lives depend on the outcomes of research.

The barriers to involvement included: a clash of ideology with service users seeking to challenge some of the common underlying assumptions in mainstream mental health research, and practical factors such as knowledge, skills and inaccessible language. A barrier to wider understanding of user involvement in research is the confusion underlying language and meanings. Some researchers continued to interpret involvement as 'participation', claiming to involve service users when in fact they were participants in the research. This issue continues to the present day as was found by the author in an exercise for INVOLVE in 2015 which examined the Research Excellence Framework (REF) 2014 database for examples of public involvement (Faulkner and Tarpey, 2015).

Reviewing the literature, the authors concluded that publication in peer reviewed journals of research involving service users was increasing, already considerably more common than at the time of the review published in the British Journal of Psychiatry two years previously (Faulkner and Thomas, 2002). Whilst there was little empirical research in the area, increasingly service user involvement in mental health research could be found in the peer-reviewed domain, and at all levels of the research process. However, far more literature was to be found in the alternative or 'grey' literature in the form of books, reports, articles, papers and web based information, much of which is produced by voluntary sector organisations. Also, it is not required for researchers to report on user involvement in publications; hence it is likely that some user/public involvement in research is hidden. The authors conclude that it is essential for researchers carrying out work in this field to take into account the extensive alternative (grey) literature: publications from voluntary organisations and user-led organisations that often do not reach, or indeed aim for, peer-reviewed journals.

2.5 FAULKNER, A. & BASSET, T. (2012) A HELPING HAND: TAKING PEER SUPPORT INTO THE 21ST CENTURY, *MENTAL HEALTH AND SOCIAL INCLUSION*, VOL.16: 1, PP.41–47. **AND**

FAULKNER, A. AND BASSET, T. (2012) A LONG AND HONOURABLE HISTORY. *THE JOURNAL OF MENTAL HEALTH TRAINING, EDUCATION AND PRACTICE*, VOL. 7: 2, PP.53 – 59.

2.5.1 THE CONTEXT FOR THE RESEARCH

In the summer of 2010, the national mental health charity Together for Mental Wellbeing (www.together-uk.org) commissioned two pieces of work exploring peer support in mental health. The first was a review of the existing literature on the evidence for peer support (Repper and Carter, 2011). The second was a small research study with users of mental health services about the benefits and challenges of peer support (Faulkner and Basset, 2010), out of which came these two publications: Papers 7 and 8. Building on the findings from these two pieces of work, Together then launched a report: 'Lived Experience Leading the Way' (Basset et al, 2010).

This work took place within a voluntary sector organisation committed to the historical value of peer support in mental health, amongst its own service users and more widely. There was an explicit political context to the work, with the goal of (re)establishing the role and value of peer support as it occurs amongst mental health service users, at a time when intentional peer support (IPS) was being developed as a new way of working within a service setting. Together has a Service User Involvement Directorate, which enabled the research to take place within a user-led context. The organisation also supported a peer-led peer support network (Peer2Peer) for a period of time until it became independent in 2014.

The research was undertaken jointly with my co-author, Thurstine Basset. I carried out the focus groups, the analysis and took the lead in writing these two papers. The full report of the consultation is given in Basset and Faulkner (2010). Thurstine Basset wrote the main report of the whole project for Together (Basset et al, 2010).

2.5.2 METHODS

With the emphasis on exploration and the understanding of meanings, the research adopted qualitative methods in the form of focus groups, undertaken with pre-formed

groups of service users engaged in different types of peer support. The first paper is based on the findings from this research and is informed by a literature review (including the learning from Repper and Carter, 2011) alongside focus groups with five service user groups engaged in different forms of peer support:

1. Peer2Peer group meeting at Together (a group of people all of whom are involved in developing or providing peer support in their localities).
2. CAPITAL (West Sussex) – a county-wide service user group providing peer support within their group and to people on inpatient wards.
3. Rochdale Borough-Wide User Forum (BWUF) – a borough-wide service user forum.
4. Rochdale WRAP (Wellbeing Recovery Action Plan) group – peer support based on WRAP.
5. Reading (Berks) Resource Peer Support Workers group – people volunteering as peer supporters within their own service.

A focus group discussion was undertaken with each group, with questions addressing the context and meaning of peer support for group members, and their views about the benefits and challenges of peer support. The questions were designed in consultation with the organisation Together for Mental Wellbeing and the project advisory group. Discussions were tape-recorded for transcription and analysis, using a modified version of Framework analysis in which a matrix was drawn up but the intermediate stages of devising an index and coding the transcripts was omitted due to the small quantity of data.

Paper 8 is a discursive and politically positioned paper based on the learning from the previous pieces of work; it explores the extensive historical roots of peer support in mental health and identifies the values and principles underpinning peer support as it occurs within service user/survivor communities. The paper covers the ground of three types of peer support, but with an emphasis on informal peer support and participation in consumer or peer-run groups as providing the grassroots foundations for empowerment, activism and the development of survivor knowledge.

2.5.3 FINDINGS

These two papers explore the changing meanings associated with 'peer support' taking place largely within the 21st Century. The first paper found that service user groups with a focus on campaigning, training, user involvement and the improvement of services saw peer support as a vital part of their group's activities, occurring spontaneously and informally between group members. A few participants were averse to the idea of formalising peer support and felt that people should not be paid to provide peer support, as this would automatically change the nature of the relationship – it would no longer be equal. Peer support, they said, should come '*from the bottom up, not top down*'. They described themselves as '*friends with something in common*' (Basset and Faulkner, 2010, p.4).

Members of these groups talked of the importance of all being 'in the same boat', or on a level with each other, the sense of solidarity that being equal members of a group gave them. Both groups also mentioned the importance of coming together with a shared cause: that of influencing and improving local services.

In contrast, for groups in which peer support was the primary focus, peer support was an intentional activity carried out on a one-to-one basis. These participants saw peer support as a more structured and intentional relationship between two people where one is offering support to the other from a basis of shared experience. People in these groups had more to say about the structures surrounding peer support: the training, support and supervision required, as well as issues surrounding the role and relationship between the supporter and the person being supported. They valued the training they had received and appreciated the boundaries they could place around their role as peer support worker.

The benefits of peer support were largely shared across all five groups. They included: having a shared identity, not being alone; increased self-confidence; the opportunity to help others; developing and sharing skills; improved mental health and wellbeing; information and signposting; challenging stigma and discrimination. Most of the challenges discussed were raised by people engaged in intentional peer support: the importance of training, support and supervision, issues surrounding employment and conflicts around maintaining a dual identity.

There were other challenges too, though, extending beyond the immediate role of peer support worker. User groups could be asked to change their role by funders or to sustain themselves against a backdrop of reduced resources. Some saw the new model of peer support to be a challenge in itself, a threat to the informal nature of peer support on offer in their own and other similar service user groups and user-led organisations.

The second paper (Paper 9) is more of an opinion piece based on a wider examination of the literature; it explores the potential for the 'professionalisation' of intentional peer support to endanger the equality that lies at the heart of peer support relationships. Independence may also be compromised if peer support becomes incorporated by mainstream services. Whilst an individual and personalised model of peer support as a means of providing services has many strengths, the authors caution against removing the opportunities for service users to meet together, support one another, plan and campaign independently of mainstream services.

The papers highlight that 'peer support', whether or not it is called this (and the terminology is variable), has been around for as long as people have needed to come together for mutual support and in all arenas of human experience (Jackson, 2010; Seebohm et al, 2013; Seebohm et al, 2010). Coming together in adverse circumstances, as in the case of inpatient wards, can create a sense of camaraderie and can be more supportive than the official treatment on offer (Walsh and Boyle, 2009; Faulkner and Layzell, 2000; Malpas and Weekes, 2001). In this sense, the new realisation of 'peer support' as an intervention in mental health services potentially neglects or obfuscates the mutual support and self-help that pre-dates it (further discussion of this takes place in Chapter Four).

2.6 FAULKNER, A. (2012) THE RIGHT TO TAKE RISKS: SERVICE USERS' VIEWS OF RISK IN ADULT SOCIAL CARE. *THE JOURNAL OF ADULT PROTECTION* VOL. 14 (6), PP.287 – 296. [EMERALD LITERATI HIGHLY COMMENDED PAPER]

2.6.1 THE CONTEXT FOR THE RESEARCH

The study behind this publication was commissioned by the Joseph Rowntree Foundation (JRF) as one of a set of scoping papers commissioned as part of their programme on risk, trust and relationships in an ageing society. The author was commissioned to explore the

views of service users and disabled people about the complex issues surrounding risk, rights and responsibility in their lives, including the right to make decisions about risk as well as the right to be protected from risk. The full report of the consultation is published on the JRF web site (Faulkner, 2012 www.jrf.org.uk/sites/files/jrf/right-to-take-risks-faulkner.pdf).

As this study was commissioned by a voluntary sector organisation, the initiative for the study was organisation- rather than user-led. However, it was undertaken within a context in which the views of service users and disabled people were being prioritised through their Independent Living User Reference Group (a group of service users and disabled people brought together to advise JRF on independent living). This group became the advisory group for the study, helping to design the questions and commenting on the findings. Once again, this study represents an unusual form of user-led research taking place within a voluntary sector context.

2.6.2 METHODS

The issue of risk has rarely been explored from a service user perspective; the unique and sensitive nature of this study determined the use of qualitative methods. People were recruited through snowballing techniques starting with the Independent Living User Reference Group, in order to reach a range of different perspectives. Nine individual interviews and one focus group were carried out, reaching a total of 17 people. These included disabled people, older people, people with learning difficulties and people with mental health problems. By observation only, the majority may be described as white British; two were Black African Caribbean. However, these views were supplemented by reference to existing literature, particularly where it helped to amplify the voices of marginalised groups or issues not reached by the consultation.

A brief topic guide was designed in collaboration with the Reference Group and the programme manager. The aim was to enable people to speak freely with little imposed structure, due to the sensitive nature of the topic and the need to understand a range of different perspectives within it. All of the interviews and the focus group were taped and transcribed for analysis. Framework analysis was used to organise and analyse the data. Findings were checked back with the participants, as was the final report in draft form. Changes were made to incorporate people's views prior to final publication.

Following publication of the final report, the paper included in this thesis was written for publication. This paper incorporates the majority of the findings, discussion and conclusions reported in the main report but with less detail about the methods used and a stronger focus on the issues arising and their contribution to service user knowledge.

2.6.3 FINDINGS

The issues raised by people in relation to risk were as follows:

- Loss of independence
- Risks in everyday choices
- Contact with services - especially for marginalised groups
- Abuse
- Disability Hate Crime
- Stigma and discrimination

Fear of different kinds was discussed by most of the participants in the study. Some talked of the fear of losing their independence, fears for their own safety when out and about, and the fear of retribution if they attempted to stand up for their rights. One man talked about the risks he faced in standing up for his rights in a residential care setting. He was 'punished' by unpleasant treatment by staff, an incident taken up by the local safeguarding board. These issues emphasise the role of power and empowerment for people in receipt of social care. Often institutional approaches and/or the fears of staff about being held to account, lead to defensive and risk-averse decisions which result in people having little choice or control over their lives.

Relationships played a significant role for some people in relation to risk. For younger disabled people, parents could be over-protective and wish to curb their independence for fear of the potential risks. Equally, older people experienced a similar dynamic in relation to their family wishing to protect them resulting in reducing their independence. For others, though, close trusting relationships could be the key to greater independence and choice, enabling people to take risks with a degree of confidence. Many people talked about the importance of finding a balance between the risks and benefits of a particular decision or action. This process could involve anything from quite small everyday decisions to major life choices.

There are several ways in which services can appear to be excluding service users and disabled people from key decisions about their lives, often in the name of protection. However, this approach has risks of its own. It can have implications for people's human rights but can also lead to less accurate information being collected and recorded, for example in the case of risk assessments.

Many people in the study talked about the importance of raising awareness and improving engagement with human rights. Several felt that a rights based approach might provide us with the means to address some of the fears and uncertainties about risk taking. People with mental health problems pointed out that they do not have the same rights as other people because of the possibility of removing their/our freedom and physical integrity through the use of the Mental Health Act: detention and treatment without consent. '*We don't even have to have lost capacity for it to happen*' (Faulkner, 2012a, p.26). The challenge lies in making human rights accessible to people in everyday language, as something that is routinely addressed and consequently easier to engage with for people who may have little power or control over their lives.

2.7 FAULKNER, A. (2005) INSTITUTIONAL CONFLICT: THE STATE OF PLAY IN ADULT ACUTE PSYCHIATRIC WARDS. *JOURNAL OF ADULT PROTECTION* 7 (4), 6-12.

2.7.1 THE CONTEXT FOR THE RESEARCH

This publication arose out of the interest and experiences of the author, stimulated by the publication of a number of survey reports on psychiatric inpatient care. The paper set out to explore some of the difficult experiences of people admitted to acute adult psychiatric wards, through positioning personal experience alongside the findings of a number of reports and surveys on the subject.

2.7.2 METHODS

The paper starts by reviewing the findings of three contemporaneous reports: by the Sainsbury Centre for Mental Health (2005); the Royal College of Psychiatrists (2005) and mental health charity Mind (2004), with reference to a fourth (the King's Fund Inquiry into London's mental health services - Levinson et al, 2003), all of which highlight poor services and disempowering treatment on acute wards. I then go on to explore how it feels to be an

inpatient through my own experiences, by selecting points of contact that illustrate the exercise of power by nurses over patients and highlighting the fine line between poor and abusive treatment. I explore the difficulties of seeking redress and finish with some suggested solutions.

The value of the publication is that the personal narrative is used to illustrate the findings of several large-scale reports, so that the picture drawn moves from the general and contextual knowledge-base to the detail of personal experience. Using personal experience in this way is common within the survivor movement, but less so within the mainstream research world. It touches on the theme and method of autoethnography (introduced in Chapter One) which is a form of writing that explores the researcher's personal experience and connects it to wider cultural, political, and social meanings and understandings.

2.7.3 FINDINGS

The paper identifies the role of power in influencing the ward environment and people's experiences within it. The findings from the reports and the personal experiences both explore poor and disempowering treatment. As the author points out:

'What this library of reports does not tell us is how it feels to be a patient on those wards, what effect being locked up for 24 hours a day without anything to do together with an unchanging routine of meals, drinks and medication and little meaningful contact with staff, might have on people.' (Faulkner, 2005, p.7)

The personal experiences highlight incidents that demonstrate the fine line that distinguishes poor or inadequate treatment and abusive treatment. The role of poor communication and inaccurate information is also explored. Finally, suggestions are made for improvements to acute care, including clear and accurate information, training for staff, clear policies and procedures on the use of drugs and alcohol. Specifically, the paper highlights the role of power in institutional life, and the need for ways of dealing with complaints and abusive treatment on acute wards. Implications are drawn for adult safeguarding.

CHAPTER THREE: CRITICAL APPRAISAL OF THE PUBLICATIONS

3.1 INTRODUCTION

In this chapter, I present a critical appraisal of the publications submitted for this thesis.

Table 3.1 sets out the publications used in this thesis, the research theme or topic, the positioning and the approach and methods used. By positioning (column 3), I refer to the way in which the research is positioned in relation to the continuum discussed in Chapter 1.3.2 where user/survivor controlled research is at one end and consultation at the other (Sweeney and Morgan, 2009). Collaborative research and user involvement in research are points in between these two polarities.

TABLE 3.1 CRITICAL APPRAISAL OF PUBLICATIONS

Publication	Theme/topic	Positioning	Approach / methods	Section
Report 1.	'Strategies for living' - i.e. ways of coping with or managing mental distress	User-led (survivor) research	<ul style="list-style-type: none"> Qualitative: depth interviews 	3.2
Report 2.	Services for people diagnosed with personality disorder	Service user involvement in research	<ul style="list-style-type: none"> Qualitative: depth interviews and focus groups Part of a large mixed methods evaluation 	3.3
Report 3.	User-controlled research	Collaborative / user-led	<ul style="list-style-type: none"> Multiple case studies 	3.6
Paper 4.	Service user involvement in research	Collaborative	<ul style="list-style-type: none"> Review of literature and practice 	3.7
Paper 5.	Services for people diagnosed with personality disorder	Service user involvement in research	<ul style="list-style-type: none"> Qualitative: depth interviews Part of a large mixed methods evaluation 	3.3
Paper 6.	Services for people diagnosed with personality disorder	Service user involvement in research	<ul style="list-style-type: none"> Qualitative: depth interviews Part of a large mixed methods evaluation 	3.3
Paper 7.	Peer support	User-led	<ul style="list-style-type: none"> Qualitative: focus groups 	3.4
Paper 8.	Peer support	User-led	<ul style="list-style-type: none"> Qualitative: focus groups with contextual review 	3.4
Paper 9.	Service users' views of risk	User-led	<ul style="list-style-type: none"> Qualitative: depth interviews and focus group 	3.5
Paper 10.	Inpatient care	User/survivor controlled	<ul style="list-style-type: none"> Auto-ethnographic -based review 	3.7

In summary, the majority of the publications (with the exception of Papers 4 and 10) employ some form of qualitative research methods. Within these qualitative research papers, the following methods are represented:

- depth interviews (Report 1, Report 2, Paper 5, Paper 6 and Paper 9);
- focus groups (Paper 7, Paper 8 and Paper 9); and
- case studies (Report 3).

CRITICAL APPRAISAL OF QUALITATIVE RESEARCH

A number of different approaches to the critical appraisal of qualitative research have been described over the years. Guba and Lincoln (Guba and Lincoln, 1981; Lincoln and Guba, 1985) developed a set of criteria for assessing 'naturalistic' studies to replace the criteria of generalisability, validity and reliability used in quantitative research: credibility, transferability, dependability and confirmability. Credibility refers to whether the findings hold true; transferability refers to whether research findings are transferable to other settings; dependability refers to whether the process and methods of research are logical and clearly documented; and confirmability refers to whether the findings can be confirmed through an audit trail of the analysis. Hannes (2011) similarly refers to these four standards for evaluating qualitative research papers. Daly et al (2007) describe four levels of a hierarchy for assessing the value of the evidence-for-practice of qualitative studies. At the bottom of the hierarchy are individual case studies, followed by descriptive studies, and then conceptual studies which analyse the data according to conceptual themes. At the top of their hierarchy are what they describe as generalisable studies which use conceptual frameworks 'to derive an appropriately diversified sample with analysis accounting for all data' (Daly et al, 2007; p.43).

There is some dispute about the idea of simply transferring criteria from quantitative research to qualitative, given the range of positions adopted by qualitative researchers and the non-standardised nature of the methods adopted (Spencer and Ritchie, 2014). Many of these approaches to appraisal have their roots in positivist research and seek assurance that the research has attempted to maximise objectivity and reduce the impact of researcher bias (Denzin, 2009; Tew et al, 2006). The traditional view of research-as-evidence is that it needs to be objective and avoid bias (Higgins and Green, 2011; Hannes, 2011). Hannes

(2011) states that *'in assessing the methodological quality of qualitative studies the core criterion to be evaluated is researcher bias'* (p.3). It is seen by many to be a limitation of qualitative research that the process may introduce elements of bias and subjectivity. Even those who recognise the value of qualitative methods may seek to reduce bias and maximise the validity of the research findings through means akin to positivist methods (Shenton, 2004).

The Critical Appraisal Skills Programme checklist (CASP, 2013; Hannes, 2011) was developed for the Cochrane Collaboration and is frequently used in the assessment of qualitative research papers. It asks ten questions of qualitative research papers:

1. Was there a clear statement of the aims of the project?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Denzin (2009) points out that CASP relies on a narrow model of qualitative inquiry: methods are not connected to interpretive paradigms (e.g. feminism, critical theory) and 'Multiple strategies of inquiry and analysis (case or performance studies, narrative inquiry, critical ethnography) go unidentified. Nor is the complex literature from within the interpretive tradition on evaluating qualitative research addressed' (Denzin 2009, p.148). He suggests that many such checklists are developed for the use of researchers unfamiliar with qualitative research. Tew et al (2006), in an exploration of values and methodologies for social research in mental health, contend that a focus on methodological rigour alone may distract attention from broader questions about the purpose and relevance of research

from the perspective of service users and carers (Hanley, 2005), a valid consideration for this thesis.

Critics of traditional research methods argue that true objectivity is rarely possible (Slade and Priebe, 2001) and may at times be harmful as a result of excluding (experiential) knowledge (Beresford, 2005; Glasby and Beresford, 2006). Many researchers have demonstrated the value of reducing the distance between researcher and researched, for example as interviewers (Rose, 2004; Clark et al, 1999; Williamson et al, 2010) and in the analysis and interpretation of results (Rose, 2004; Gillard et al, 2012a; 2012b; Allam et al, 2004; Faulkner et al, 2008). Knowledge is co-created in the space between the researchers and the researched (Tew et al, 2006; Denzin, 2009). Glasby and Beresford (2006) argue that objectivity and distance (between the researcher and those being researched) can be harmful in some circumstances, reducing the possibility of participants being able to speak openly and leading to the distortion or misunderstanding of the experiences being interpreted. Similarly, Rose (2009) points out that all research comes from a particular standpoint (or perspective); she argues for the recognition of different standpoints alongside challenging traditional notions of credibility, validity and legitimacy.

In this thesis, many of the papers represent research that relies upon the view that there is positive value in service users-as-researchers and an explicitly service user/survivor 'standpoint', thereby reducing the distance (and the power relations) between the researcher and the researched (Glasby and Beresford, 2006; Beresford, 2003; Tew et al, 2006). Whilst this has the potential to challenge traditional views of objectivity and bias, it follows in the tradition of emancipatory research (Barnes and Mercer, 1997; Beresford and Wallcraft, 1997) which argues for the potential empowerment of people who might ultimately be the beneficiaries of the research. The research in this thesis can be seen as a contribution to the collective knowledge of the service user/survivor movement, as one example of a 'new social movement' (Humphries, 2000a). This research follows the aim of such movements to 'make visible those experiences which are misrepresented or ignored by official statistics and by methodological assumptions which result in normative ideas about family life and household structure' (Humphries, 2000a p.10). In other words, it is potentially transformative research, explicitly seeking to challenge our understanding of the existing (psychiatric) paradigm.

APPROACH TO CRITICAL APPRAISAL USED IN THIS THESIS

As a result of these reflections, the structure I have chosen for critically appraising these publications is one based on a simple set of guiding principles, rather than an approach rooted in positivist research. Spencer and Ritchie (2014) identify three guiding principles which they identify as recurring across many of the frameworks proposed for appraising the quality of qualitative research: *contribution*, *credibility* and *rigour*.

- *Contribution* refers to the value and relevance of the research, an enhancement of existing understanding - or 'enlightenment' (Spencer and Ritchie, 2014, p229). I will use this element to explore both the emancipatory purpose (Tew et al, 2006) of the research and the contribution that it makes to the collective experiential knowledge of the service user/survivor movement (Costa et al, 2012; Humphries, 2000a; Noorani, 2013). (The contribution of this body of work as a whole is addressed in Chapter Four).
- *Credibility* relates to the defensibility and plausibility of the claims made by the research. This relies on transparent representations of the data and an understanding of how conclusions were reached on the basis of the data.
- *Rigour* refers to the use of reflexivity, the auditability of the account and the defensibility of the approach and design.

These guiding principles will be used to appraise the qualitative research papers in this thesis, alongside necessary references to the role of the service user-as-researcher. This is followed by the review and discursive papers (Papers 4 and 10) which will be appraised using the TAPUPAS framework (Pawson et al 2003). An alternative framework for critical appraisal was developed by Pawson et al (2003) in order to address the need for a generic framework suitable for the social care knowledge base. Its value lies in understanding the full range of sources of knowledge that might be taken into account: organisational, practitioner knowledge, service user knowledge, research knowledge and knowledge originating from the policy community. The aim of this framework is to acknowledge that there are a range of different sources of knowledge that need to be judged 'within a framework that respects the wide diversity of views on quality within the social care community' (Pawson et al, 2003, p. viii). The framework TAPUPAS is outlined below:

- Transparency - are the reasons for it clear?

- **Accuracy** - is it honestly based on relevant evidence?
- **Purposivity** - is the method used suitable for the aims of the work?
- **Utility** - does it provide answers to the questions it set?
- **Propriety** - is it legal and ethical?
- **Accessibility** - can you understand it?
- **Specificity** - does it meet the quality standards already used for this type of knowledge?

The value of this framework is that it gives explicit space and weighting to knowledge generated by service users. During testing it was found that 'use of the TAPUPAS schema forced consideration of the strengths and weaknesses of each document and broadened the common notion of quality and quality assessment to sources beyond the traditional research domain' (Long et al, 2006, p.207). As such, it is a useful framework for the less traditional publications in this thesis: papers 4 and 10.

3.2 REPORT 1: 'STRATEGIES FOR LIVING WITH MENTAL DISTRESS'

METHODS

Full details of the methods are given in 2.1.2. Here, the methods are summarized as a precursor to the critical analysis. 'Strategies for Living' was a large user-led qualitative study, involving depth interviews with 71 people who identified variously as experiencing mental distress, mental health problems or using mental health services. A qualitative research approach was indicated in order to reflect the exploratory nature of the study; we did not wish to place pre-defined categories or boundaries on the potential responses and wanted to hear people's stories. Individual depth interviews enabled us to retain contact with the experiential reality of people's lives and the essence of personal stories, whilst enabling us to draw out common themes through the Framework approach to analysis (Ritchie and Spencer, 1994; Ritchie et al, 2014). We were also in a position to follow up themes arising from the preceding survey 'Knowing Our Own Minds' which reached 401 people (Faulkner, 1997).

Qualitative research of this kind enables us to understand the meanings and the context of people's stories, without imposing a pre-conceived structure upon them; it is also indicated

in situations where little is known about a phenomenon or to gain new perspectives, as in this case (Gray, 2014). Qualitative research enables us to understand experience and processes (Harper and Thompson, 2012). Although the term qualitative research covers a broad range of theoretical and practical approaches, in general its purpose is to provide an in-depth understanding of our social world, by learning about people's experiences, perspectives and histories (Ritchie et al, 2014). The aim is to generate insight, understand how people think and feel and understand the meanings they place on their own behaviours (Williamson, 2009). Qualitative research methods are often chosen by survivor researchers, as they are keen to give their participants and peers the space and time to tell their stories, to give their views freely without the constraints of pre-defined questions or measures frequently designed by professionals (Faulkner, 2012b; Faulkner, 2015).

The aim of this research was to invite and enable people to talk about how they managed their lives, what they found helpful and how they lived with mental distress. We wanted to enable people to talk about what was important to them without the imposition of pre-conceived ideas. We employed five service user/survivor interviewers to carry out the interviews, to develop the topic guide and to contribute to the analysis and report. The purpose behind this was to reduce the distance and the power relations present in the interview situation: a situation that is in danger of replicating the power relations inherent in the clinician/patient relationship (Beresford, 2005; Beresford and Rose, 2009).

The interviews were analysed using the Framework approach (Ritchie and Spencer, 1994; Gale et al, 2013). Interviews were entered on the computer package for qualitative data NUDIST (Richards and Richards, 1990), and we used Framework to analyse the stored data.

CONTRIBUTION

The 'Strategies for Living' programme has been described as 'ground-breaking' for its pioneering approach to service user/survivor research and for the capacity building it supported for local service user research projects (Beresford and Boxall, 2013, p.75; Beresford and Rose, 2009, p.17). Sweeney (2009) refers to 'Strategies for Living' as one of the two programmes of research that began to establish service user research in the UK (the other being User-Focused Monitoring at the Sainsbury Centre for Mental Health (Rose, 2001)). Both programmes, she says, aimed to represent service users' stories and to conduct

high quality research, without losing the activist element in generating service user knowledge (Sweeney, 2009, p.29). Wallcraft (2007) describes 'Strategies for Living' as 'the biggest and most influential project' of research-based alternatives to psychiatry (Wallcraft, 2007 p.345). Dr Philip Thomas, at the time consultant psychiatrist in Bradford, referred to it as 'the definitive statement about expertise by experience' (quoted in Mental Health Foundation, 2000, p.1). At the time of writing, the report has received 193 citations on Google Scholar.

The 'Strategies for Living' research made a significant contribution to the body of knowledge created by service user and survivor researchers in mental health. In the tradition of emancipatory research (Barnes and Mercer, 1997; Beresford and Wallcraft, 1997), this research started from the basis of service user knowledge about experiencing distress and finding ways of coping and surviving. Tew et al (2006) talk of the 'emancipatory purpose' of mental health research: that research will enable service users and survivors to gain a greater awareness of their situation so that they can make informed decisions and choices; have more control over the direction of their lives; participate more in social, economic and political life and can enable them, in conjunction with practitioners and members of the wider community, and to challenge stigma, injustice and social exclusion (Tew et al, 2006, p.vi).

The programme of work surrounding 'Strategies for Living' contributed to many of these areas, and hence realised this emancipatory purpose. We learned from the expertise of people living with mental health problems, and shared that expertise with other people in the wider service user community through newsletters, publications and conferences in the spirit of 'community-owned research' discussed more recently by Jones et al (2014). A major part of the programme as it developed became the support offered to local service users and user groups to carry out their own research (Nicholls et al, 2003).

The research was ground-breaking in that it was the first substantial research project in this country carried out by people who identified as mental health service users or survivors at that time. It was unique also in building upon the previous 'Knowing Our Own Minds' survey (Faulkner, 1997), it looked at survival or coping strategies from the perspective of service users. The main contribution of 'Strategies for Living' was to foreground the knowledge of

mental health service users about their/our experiences and expertise. By highlighting the different ways that people had found (and continue to find) for living with their experiences of mental distress, the research challenged the dominance of psychiatry and the biomedical approach to mental illness (Armes, 2009). Further than that, it was service users and survivors who carried out the analysis as part of the move to become the 'knowers' in the production of knowledge (Russo and Beresford, 2014).

Many of the findings presented in this report have since been echoed in recovery research (Brown and Kandirikirira, 2007); in some ways, this project was a precursor to recovery research in the UK. Themes such as acceptance and purpose, shared identity, control and choice have become pillars of the mental health recovery approach (Brown and Kandirikirira, 2007; Ajayi et al, 2009; Bowyer et al, 2010). The recovery approach was developed in the U.S. in the 1990s and originated in the lives of people experiencing mental distress (Deegan, 1996b). Recovery has been defined in many ways, but is generally presented as a way of 'way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness' (Anthony, 1993) or as a personal journey towards rebuilding a satisfying and meaningful life with or without ongoing symptoms of mental distress.

At the time of this programme of work the Mental Health Foundation was involved in staff training through publishing materials and accrediting, through City and Guilds, a UK-wide Certificate in Community Mental Health Care. The findings from the Strategies for Living research were included in this initiative. Also the Foundation founded and supported a Mental Health Trainers Network; a training package based on the findings of Strategies for Living was written and made available on the website for this network.

CREDIBILITY

Methodological credibility is demonstrated by the stratified purposive sample, further details of which are given in 2.1.2. The 76 people were selected to reflect the range of backgrounds and experiences identified by the 'Knowing Our Own Minds' survey and reasonable success was achieved. Five interviews were of insufficient quality to be included and fewer African Caribbean participants were obtained than were aimed for (nine out of

15). The sample excluded people currently in hospital or other secure accommodation as the research did not obtain ethical permission to access these services.

The interviewers were all trained in depth interviewing by members of the Qualitative Research Unit of NatCen (Jane Ritchie and Kit Ward). The interviews were tape-recorded and transcribed for analysis using a widely accepted method for analysing qualitative data: framework analysis (Ritchie and Spencer, 1994; Ritchie et al, 2014).

Framework analysis employs a rigorous and transparent means of organising the raw interview data and identifying themes that emerge from the data. The Framework approach is appropriate for thematic analysis of interviews, where it is important to be able to compare and contrast data by themes across many cases, while retaining the context and contextual elements of each participant's account (Gale et al, 2013). All of the interviews were entered on the computer package NUDIST and categories and themes were identified and analysed accordingly. The primary analysis was undertaken by the author; themes were checked back with the five interviewers and the report written on the basis of the agreements reached. However, greater credibility would have been achieved if analysis had been undertaken by a team and more detailed cross-checking had been undertaken.

A different kind of credibility relates to the origins and placement of this research within the mental health service user/survivor community. The research gained credibility within this wider community, and, as mentioned earlier, was seen as groundbreaking by service user/survivor researchers and peers (Beresford and Boxall, 2013; Beresford and Rose, 2009; Sweeney, 2009; Armes, 2009). Arguably, it also established credibility with participants through the active involvement of service user interviewers as is demonstrated in the reflexive approach undertaken by the researchers (see Rigour below).

One of the limitations of the research is that the use of framework analysis deconstructs people's narratives into themes, and, whilst this makes it easier to understand differences and similarities between people's accounts, particularly where there is a large number of interviews, it makes it harder to retain the wholeness and individuality of people's narratives (Gale et al, 2013). An interesting follow-up to this report would have been to return to the data and explore a sub-sample of whole narratives working with the

participants to build a different kind of understanding of people's 'strategies for living' within the context of their lives.

RIGOUR

For Spencer and Ritchie (2014), rigour in qualitative research refers to the use of reflexivity, the extent to which the account of the research is auditable and the defensibility of the approach and design. Reflexivity refers to the ability to 'engage critically in understanding the contribution the researcher's experiences and circumstances have had in shaping a given study (and its findings)' (Harper and Thompson, 2012, p.6). Unlike quantitative research, where the underlying assumptions concern objectivity and the minimisation of bias, in qualitative research the role of the researcher is acknowledged and their beliefs and values made explicit (Ritchie et al, 2014; Denzin, 2009). In some (positivist) approaches to qualitative research, the purpose of reflexivity is to reflect and report upon these as potential sources of bias (Hannes, 2011), whereas in most of the research explored in this thesis, the purpose is to make explicit the role *and value* of the service user as researcher with that particular perspective and standpoint (Rose, 2004, 2009; Glasby and Beresford, 2006; Williamson et al, 2010). As stated by Shaw (2010):

"Through making ourselves aware of our own feelings about and expectations of the research we can begin to fully appreciate the nature of our investigation, its relationship to us personally and professionally, and our relationship as a researcher and experiencer in the world to those with whom we wish to gather experiential data." (Shaw, 2010; p. 237)

In *Strategies for Living*, all of the service user researchers and interviewers took part in a reflexive exercise, reported in Chapter 6 of the report (pp96-105). This included reflections about the impact on both interviewers and interviewees of carrying out the research in this way and the emotional impact of carrying out the interviews. Furthermore, one black interviewer described his personal and political dilemmas in relation to black researchers 'giving information to white institutions' (p.103) and the implications of purchasing 'the insight of blackness through the payment of £15' (p.103).

However, this approach did not constitute fully embedding reflexivity within the research, as advocated by Shaw (2010). She describes Woolgar's (1988) continuum of reflexivity from

benign reflection/introspection through to 'radical constitutive reflexivity' (Shaw, 2010 p.234). By benign reflection, the authors refer to the essentially positivist aim to present an 'accurate' representation of the interviewees' accounts. 'Radical constitutive reflexivity', on the other hand reflects the 'postmodern stance that reality is constructed contemporaneously and no account (whether the researcher's or the participant's) can be valued over another' (Shaw, 2010, p.236). It involves an explicit evaluation of the self in the co-construction of meaning. I would position the reflexivity undertaken in Strategies for Living somewhere in between these two polar positions.

The research methods were reported adequately and transparently; however, the report did not present raw data from the detailed stages of analysis. Excerpts of framework tables or raw data could have been included to demonstrate the transition from the organisation of the data to the elucidation of themes (Spencer and Ritchie, 2014). The themes were checked back with interviewers and two people were involved in the interpretation of the results for the purposes of report-writing. Individual respondent validation - another approach to validating qualitative research - was not possible in this case due to the large and geographically widespread sample.

3.3 REPORT 2 LEARNING THE LESSONS: A MULTI-METHOD EVALUATION OF DEDICATED COMMUNITY-BASED SERVICES FOR PEOPLE WITH PERSONALITY DISORDER; WITH PAPERS 5 & 6

METHODS

The detailed methods for this study are given in 2.2.2. The entirety of the research reported in Report 2 'Learning the Lessons' was a mixed methods evaluation of 11 community services for people with a diagnosis of personality disorder led by Professor Mike Crawford at Imperial College, London University. The author was involved in Module 3: the qualitative investigation of the views and experiences of people using these services and their carers, undertaken by the Mental Health Foundation. This study-within-a-study involved in-depth interviews and focus groups with service users who were currently using the services, service users who had previously used the services, and carers of people who were using or had used the services. A purposive sampling technique (detailed in section 2.2) was used

within the context of the defined populations of people using these services, to ensure representation of the full range of potential perspectives and to include perspectives of minority groups.

Paper 5 sets the qualitative data from the different modules in context to identify factors contributing to high quality care for people with a diagnosis of personality disorder from the perspective of different stakeholders. The paper reports on the qualitative interviews undertaken with service users, carers, providers and commissioners of services at each of the 11 sites and hence draws heavily upon the user-led module.

Paper 6 reports on the process of involvement of the service user researchers (from recruitment through training and support to analysis and interpretation) and their reflections on being involved in this study.

The use of qualitative interviews for the module in which the views and experiences of service users and carers were explored, was an appropriate application of qualitative methods. It sat alongside a range of other methods that sought to establish the views of staff and other stakeholders and the outcomes for service users of using the services. Looking at the entire study, which consisted of four modules, this meant that the information about the services was triangulated with reference to different sources of knowledge.

CONTRIBUTION

The pilot services being evaluated in this research were innovative in providing new models of care and treatment for people with a diagnosis of personality disorder. This diagnosis has frequently been used to refuse services to people, as it has been used by some professionals to designate people as 'untreatable' (Haigh, 2002; Ramon et al, 2001). However, NHS policy and practice was changing at this time to explore the contention that therapeutic approaches might be appropriate for some people with a diagnosis of personality disorder. In January 2003, the National Institute for Mental Health (England) published its policy implementation guidance on services for people with personality disorder: *Personality Disorder: No longer a diagnosis of exclusion* (National Institute for Mental Health, 2003). This built on the National Service Framework for Mental Health's standards four and five (Department of Health, 1999) on effective services for people with severe mental illness. In

2005 the Department of Health commissioned a range of new services for people with a diagnosis of personality disorder: five largely residential specialist forensic services and 11 community-based 'pilot' services. The community based services were asked to develop innovative interventions that promoted personal recovery and social inclusion for people with a diagnosis of personality disorder. The 11 community-based services were the subject of this study.

The contribution of this study, then, was at least two-fold. Firstly, it represented the gathering of experiences and views from present and past service users and carers about a set of innovative services for people previously (largely) excluded from services. The research has since been referenced in documents developed to support people with a diagnosis of personality disorder (for example: Bolton et al, 2014). Secondly, the research module undertaken by the Mental Health Foundation was innovative in that it was entirely led and carried out by service user researchers and interviewers. This study was both radical and conventional. It used conventional qualitative methods and was located within a NIHR funded university-based study based on a biomedical understanding of the 'personality disorder' diagnosis. Consequently, it required a certain amount of compromise on the part of service user researchers many of whom did not agree with the biomedical approach to mental health underlying the diagnosis. An example of this is the following sentence in the introduction to Paper 5: *'People with personality disorder (PD) have maladaptive patterns of relating to self and others which have negative consequences for the individual and society at large.'* (Paper 5: Price et al, 2009 p.467). This is not something that the service user researchers would have written or agreed with. Nevertheless, the user-led module had a significant degree of autonomy from the main study, and was led by service user researchers with support from the Mental Health Foundation. Service user researchers gained skills and knowledge during the course of the study, and engaged many service users' views through the interviews about the services they were using.

CREDIBILITY

The user-led module was undertaken with a fully transparent audit trail through the analysis from the data collection to the report, detailed in section 2.5, pp28-31 in the full report (Crawford et al, 2007). Each service user researcher involved in the analysis of their own sites was supervised by one of the two senior researchers (AF and SG); themes were

checked and new themes added with reference to the other researchers engaged in the analysis. All such decisions, the analysis and themes arising were recorded in order that they could be fully audited by the research team at Imperial College if necessary. A limitation of the research was that, given the number of services involved and their geographical spread, it was not possible to check the emerging themes and findings back with the participants. The opportunity to build this stage into the research would have given the findings an extra layer of credibility.

Lewis et al (2014), in writing about evaluating the quality of qualitative research, usefully distinguish between three types of generalisation: representational generalisation (whether what is found in a research sample can be generalised to, or held to be equally true of, the parent population from which the sample is drawn), inferential generalisation (whether the findings from a particular study can be generalised, or inferred, to other settings or contexts beyond the sampled one) and theoretical generalisation (in which theoretical propositions, principles or statements may be drawn from the findings of a study for more general application).

I would argue that the research reported in these publications satisfies the criterion of representational generalisation, in that the research sample can reasonably be generalised to, or held to be equally true of, the parent population from which the sample is drawn (the parent population being all people who had used, or were using, these new services). However, it did reach them at a particular point in time which for a small number of the services may have been too early, i.e. before they had become fully established. One of the limitations of the study was that the services were pilot services and had yet to fully develop their service and therapeutic approach (Report 2: Crawford et al, 2007). A longer term follow-up would have been valuable in revealing the value of the services to people as they became fully established.

This module also established significant credibility with service user and survivor researchers. Those involved in the research were appreciative of the careful and supportive process with which we engaged them in the work (documented in Paper 6). It was ground-breaking in being a large and rigorous user-led study within a large NIHR programme grant.

Nevertheless, the user-led module became less visible within the context of the wider dissemination, which became the preserve of the academic research leads.

RIGOUR

This study represents a rigorous approach to qualitative research, led by service user researchers located within a larger mixed-methods study. The researchers involved throughout the study took a reflexive approach towards their experiences of the research and research process, to begin to understand the role and impact of employing user-led methods (Shaw, 2010; Alvesson and Skoldberg, 2009; Carr, 2013). Much of this reflexive learning is reported in Paper 6.

Many of the researchers and interviewers involved had direct experience of a diagnosis of 'personality disorder'. We began the training by reflecting on the learning that we brought to the research from this experience, and the different views that we had about the diagnosis. It was vital to bring these views to the forefront of our minds in order to enable us to be aware of our own perspectives within the context of hearing the views being expressed by the research participants. This is rarely done in traditional research, where distance and objectivity are valued over and above the perspectives brought by individual researchers. As a team, we identified the elements we felt we had learnt about user involvement or that we felt had contributed to the body of knowledge of 'user involvement in research'. In particular among these was the value of being involved in the analysis as well as the interviewing; we felt that this both added to our own learning and ensured an extra level of validity to the findings. Some members of the team were keen to point out that the process had helped to challenge stereotypes about service users and what they/we can and cannot do.

In the analysis stage, we were rigorous in reflecting on the findings and validating our interpretations of them as a team; each stage was supervised by a member of the research team and all decisions were recorded. There is a clear audit trail from the data through the analysis to the emerging issues and conclusions, which both makes the findings credible and the research potentially replicable (Spencer and Ritchie, 2014).

3.4 PAPERS 7 AND 8: PEER SUPPORT

METHODS

Papers 7 and 8 both relate to research carried out by the author with five service user groups exploring their views and experiences of peer support, on behalf of the mental health charity Together for Mental Wellbeing. The methods and findings are detailed in section 2.5.2. Paper 7 reports on the study directly; it reached five service user groups comprising a total of 52 service users (37 women and 15 men). The groups were selected by the advisory group to represent different approaches to peer support from a database of groups and organisations kept by Together. An awareness of the different perspectives and approaches to peer support, meant that the groups were chosen to include both group and one-to-one approaches, as well as 'intentional' peer support and mutual or informal approaches. One group was a national network of people providing peer support in their localities, coming together to discuss policy and principles underlying peer support. Another was a service user group providing peer support both within their own group and as a commissioned service to people on inpatient wards. One was a borough-wide service user forum, again supporting each other. The remaining two provided different forms of predominantly one-to-one intentional peer support, one based on WRAP (Wellbeing Recovery Action Plan) and the other engaging people to volunteer as peer supporters within their own service.

Paper 8 reports the research alongside an exploration of the relevant literature, positioning the study within the political context and the national policy surrounding peer support in mental health in the UK (see below).

CONTRIBUTION

One of the main contributions of this study was to place firmly on the map the peer support that takes place within different informal and voluntary sector contexts, as distinct from the growing body of peer support practice based within mental health NHS services (Repper and Carter, 2011; Gillard et al, 2013; Simpson et al, 2014). These two papers and the study they report are significant in giving voice to the views of service users and user groups for ownership of the peer support that we/they have valued over the years (Jackson, 2010; Faulkner and Kalathil, 2012; Beales, 2012). Peer support (like Recovery before it) has been in

danger of being co-opted by mental health services into something that is designed by professionals and requires particular qualifications and experience to perform (Crepaz-Keay and Cyhlarova, 2015).

This study (alongside other initiatives undertaken by Together for Mental Wellbeing, Mind and NSUN) has helped to place a marker in the ground that claims part of the peer support arena for service user and survivor-led definition. As an example, the scoping research conducted by Mind as the cornerstone of its peer support programme quotes from these papers extensively (Mind, 2013). The Mind peer support programme went on to receive £3.2 million from the Big Lottery Fund to improve local access to peer support across England. The programme that built on this research, now called Side by Side, has since funded 37 local peer support projects. In addition, Together for Mental Wellbeing developed a Peer Support Training programme accredited by Middlesex University which is still operational today.

Peer support is, I would argue, the bedrock of experiential knowledge and consequently a vital space in which we sustain the user/survivor movement. Some writers on the broader history of self-help and mutual aid highlight its role in the formation of experiential knowledge as a challenge to professional, scientific knowledge (Dawney, 2011). As referred to in 1.1, Borkman (1990) describes experiential knowledge as based on having undergone specific and affecting life experiences, arguing that it is '...specialised knowledge, grounded in an individual's lived experience' (Borkman, 1990, p.3). Borkman further distinguishes 'experiential authority' as the legitimisation of knowledge gained through personal experience, the process through which it matures and gains credibility. She highlights the power people gain to 'take their own and their peers' stories seriously' (Borkman, 1990, p.7) in the self-help spaces where they develop experiential authority.

Peer support has emerged in recent years as a new way of providing services and employing people with lived experience in peer support roles to support their peers (Repper and Carter, 2011; Simpson et al, 2014; Gillard et al, 2013). However, this structured or intentional model is not what peer support has traditionally meant to people experiencing mental distress. The concept has been around for a very long time and in many different contexts (Borkman, 1990; Noorani, 2013; Jackson, 2010). That it has been re-invented and

co-opted by mental health services is an example of what happens when experiential knowledge is largely absent from research, policy and service development (Penney and Prescott, 2016; Russo and Beresford, 2014). In this sense, these two papers describe the emancipatory purpose of the underlying research (Tew et al, 2006).

CREDIBILITY

The methods used to collect and analyse the information are not made explicit in these papers, which is a limitation in relation to credibility (Spencer and Ritchie, 2014). Seale (2012), for example, argues that good practice in relation to establishing the validity of qualitative research can be achieved by demonstrating well-grounded links between the data and the concepts and conclusions the researchers have developed. Indeed, one of the key strengths of qualitative research lies in its ability to describe a phenomenon in the authentic language and meanings of the participants. Whilst this latter is achieved in these papers, the links between the raw data and emerging concepts are not made explicit. The methods were detailed in the original report of the consultations published by Together for Mental Wellbeing (Faulkner and Basset, 2010), but this level of detail was not considered necessary for the papers presented here. To some extent, this treatment of the methods is influenced by the context of the research and publications (see 1.3.3): the voluntary sector organisation commissioning the research and the journals chosen for publication. Where the emphasis is on reaching frontline practitioners and service users, the journal rarely gives the same priority to detailed methodology that would be encountered in a higher impact and higher status academic journal.

A qualitative study of this kind is limited by the number of groups and individuals reached, a limitation balanced by their careful (or purposive) selection to ensure the inclusion of particular perspectives. The groups chosen here were all different in their approach to peer support, although with some common themes. However, without a comprehensive overview of the different types of peer support available, there may be significant gaps in the knowledge achieved through a consultation of this kind. One such gap in this case was peer support provided within BME and other marginalised communities, a gap that was subsequently filled in another piece of work undertaken for the same organisation (Faulkner and Kalathil, 2012).

The study and the accompanying materials published by Together for Mental Wellbeing (Faulkner and Basset, 2010; Basset et al, 2010; Repper and Carter, 2011) were attributed credibility within the service user/survivor community and voluntary sector by virtue of the organisation funding and producing them. Together is alone amongst the large mental health charities in having a Service User Involvement Directorate within the organisation which undertakes user-led work throughout and beyond the organisation. Together was also responsible for supporting the development of NSUN (the National Survivor User Network), the user-led mental health network.

RIGOUR

The methods were appropriate in that an exploratory approach was indicated by the need to understand from a service user perspective the different approaches to peer support taking place in the different contexts. Qualitative methods are indicated in situations where little is known about a phenomenon or to gain new perspectives, as in this case (Gray, 2014). Focus groups are indicated where research needs to reach a reasonable number of people and does not require in-depth detailed information from individuals. Rather, this method is predicated on the value of the interaction between participants lending something more to the findings than would be gained through individual interviews. Participants have the opportunity to hear the views of other people in the group and to reflect upon and develop their own views in response (Finch et al, 2014). The value of focus groups lies in gaining insight into people's shared understandings of a particular phenomenon or experience and the ways in which participants develop their ideas in relation to the views of others in the group situation (Gibbs, 1997). In this project, it was considered appropriate to use focus groups because the aim was to gain some shared understandings within each group of their particular approach to peer support.

The groups were recruited through a snowballing or networking approach and the group discussions were guided by a topic guide consisting of a series of open questions. The topic guide was developed by the researchers in conjunction with the Project Advisory Group and based on current issues in the literature. The discussions were recorded and transcribed for analysis using a modified version of Framework Method; an index was not developed but the information was organised in a matrix to organise the emerging themes. The reason for this was pragmatic: there was not a lot of data and this made it easier to organise it without

recourse to a process of systematic coding. However, it is possible that minority issues could have been missed as a result of this less rigorous approach to analysis.

3.5 PAPER 9: THE RIGHT TO TAKE RISKS

METHODS

Paper 9 reports an exploratory study funded by the Joseph Rowntree Foundation, involving one focus group and nine individual interviews, reaching a total of 17 people with experience of using mental health and/or social care services. People were recruited through snowballing techniques starting with the Joseph Rowntree Foundation's Independent Living User Reference Group, in order to reach a range of different perspectives. These were supplemented by reference to the existing literature, particularly where it helped to introduce the voices of marginalised groups or issues not reached by the consultation. Further detail of the methods is given in section 2.6.2.

The pre-formed User Reference Group was seen as a practical place to start the research, as the group was familiar with talking about the often sensitive issues associated with the challenges of achieving independent living together. This formed the initial advisory group with which the topic guide was designed and from which the snowballing for recruitment of interviewees began. The aim was to reach a range of 'expert views' with which to inform the development of the Joseph Rowntree Foundation programme: they wished to reach people familiar with articulating these complex issues. The approach taken to both the interviews and the focus group was in-depth and unstructured. Discussion followed a topic guide designed to cover the themes of risk, rights, responsibilities and relationships, reflecting the underlying conceptual framework of the Joseph Rowntree Foundation work programme.

CONTRIBUTION

This paper was awarded an Emerald Literati 'highly commended' award for 2013 at least in part because of its significant contribution to the knowledge base. It was possibly unique at the time in filling a significant gap in knowledge, in that the views of service users about risk have been rarely sought directly. Research and policy regarding risk has tended to reflect an exclusively professional or organisational/administrative agenda (Carr, 2010; Wallcraft and Sweeney, 2011). Prior to this small study, very few previous studies had engaged directly

with disabled people or service users about risk. The significance of this lies in the study's ability to identify additional and different risks to those commonly identified by professionals and policy-makers, as well as some suggestions for addressing them. It also highlights the greater potential for addressing concerns about risk where it is discussed openly with those whom it most directly concerns: the disabled people or service users whose risk, rights and safety are in question. The study revealed the extent of people's fears, particularly the fear of losing independence in the context of a risk-averse society and risk-averse services intent on avoiding harm at all costs. The costs to people's quality of life within the context of this approach are considerable. The study concludes by suggesting that, for services to be genuinely person-centred, individual assessments and reviews need to have independence as their starting point.

"It is vital that we hear more from service users and disabled people in this complex arena, not just about their (our) perceptions of risk but also about our views and perceptions of rights and responsibilities. We have a right to take many of the same risks as anyone else – and a right to have our rights recognised." (Faulkner, 2012, p.295)

CREDIBILITY

The paper does not make explicit the methods used to capture and analyse people's views; hence the process through which the findings were reached is not transparent. In fact the interviews and the group discussion were all recorded and transcribed for analysis, but this is not reported in this paper. This compromises the credibility of the research, in that the relationship between the data and the concepts and conclusions reached is not made explicit (Spencer and Ritchie, 2014; Seale, 2012). This makes it harder to judge the credibility or validity of the research. In addition, it was a very small study and by no means 'representative' of the population of people who are covered by these issues. It did not reach some people whose voices are seldom heard, such as people in secure accommodation.

The study achieved credibility amongst the service users and survivors who participated in it due to the inclusivity of the process, in line with the principles of survivor and emancipatory research (Beresford and Wallcraft, 1997; Sweeney, 2013; Russo, 2012). I undertook the

work from an explicit service user/survivor perspective and made notes of the interviews and the focus group available to the participants so that they could add to or amend their views if they wished. All participants were given the opportunity to comment on the findings and the final report to the Joseph Rowntree Foundation. These comments were taken into account which gives the paper added credibility and validity from the perspective of participants, often referred to as 'respondent validation' (Lewis et al, 2014; Lincoln and Guba, 1985).

RIGOUR

The study demonstrated rigour in the form of active reflexivity on the part of the author and the defensibility of the methods and design. In both the main report and in this paper, I reflected on the role of risk in my own life in relation to experiences of mental distress and mental health services, and introduced this into the interpretation and understanding of the study (Shaw, 2010; Alvesson and Skoldberg, 2009). The choice of qualitative methods in the form of depth interviews and focus group was appropriate for a theme so little examined, and which needed a sensitive, exploratory approach. Individual interviews were chosen in order to enable full exploration of sensitive issues about people's lives. We needed to reach people with different backgrounds and relationships with social care services. The focus group provided a useful means of both starting and finishing the research, in that it became a springboard for the initial design of the topic guide, a rich source of data and a means with which to validate the findings and the final report. The individual interviews were chosen in part to fill gaps in experience, service use and disability not covered by group participants.

3.6 REPORT 3: CHANGING OUR WORLDS: EXAMPLES OF USER-CONTROLLED RESEARCH IN PRACTICE

METHODS

'Changing Our Worlds' was a collaborative study (between the author as survivor researcher and the INVOLVE project team) of user-controlled research. It used a multiple case study approach in order to explore seven examples of user-controlled research. This approach was appropriate for the task as it enabled cross-case comparison of a sample of projects employing a 'user-controlled research' approach according to agreed criteria (see 2.3.2). Furthermore, a multiple case study approach enabled the project to consider dissemination

with the aim of achieving wider awareness and understanding of the role and value of user-controlled research.

Typically, case studies involve the collection of data from a variety of sources (Gray, 2014). They explore subjects and issues where the aim is to understand the relationship between a phenomenon and the context in which it is situated (Gray, 2014). Yin (2009) talks of the case study as exploring a situation where the boundaries between the phenomenon and its context are not clear. This is particularly relevant to Changing Our Worlds, where the aim was to examine a small number of examples of user-controlled research (Turner and Beresford, 2005¹), to explore what distinguished them as 'user-controlled', why they had been conducted in this way and what factors had contributed to their successful execution. Each study had taken place within its own unique context, initiated by a small group of service users or disabled people, or a small organisation with limited resources. The study explored common themes, facilitators/drivers and barriers to user-controlled research through individual and small group interviews, and document analysis.

CONTRIBUTION

The unique contribution of Report 3 'Changing Our Worlds' was to place 'user-controlled research' on the agenda, both of the primary UK organisation championing public involvement in research (INVOLVE) and of the wider NIHR community. It has received 21 citations on Google Scholar, including citations in papers that explore the impact of service user involvement in research (Evans, 2014; Staniszewska et al, 2011). It also gave a new dissemination platform to the individual projects. As pointed out by Turner and Beresford (2005), user-controlled research has been marginalised by the public involvement agenda. Funding is channelled into research organisations which involve patients and members of the public in clinical academic research, but usually perpetuate existing paradigms. Rarely is user-controlled research prioritised in this way. 'Changing Our Worlds' demonstrates the ways in which small organisations and marginalised communities have found to carry out research placing their communities and issues of concern to them on the map. Humphries (2000b) suggests that what is required is 'research which 'brings to voice' excluded and marginalised groups as subjects rather than objects of research, and which attempts to

¹ User-controlled research is research undertaken within the full control of people who identify as health or social care service users or disabled people (Turner and Beresford, 2005). See also 1.3.1.

understand the world *in order to change it*' (Humphries, 2000b; p.182). Each of the projects represented in this report managed to achieve this within their own context. The report extended this learning by looking across the case studies and identifying themes to explore and explain their significance, such as: empowerment, access and trust, credibility, dilemmas of identity and power, and discrimination.

The study could have made a more significant contribution through being written up for publication in peer-reviewed journals and/or disseminated more widely for service user and disabled people's audiences. For example, the report could have been made available to a wider range of disability and mental health survivor organisations, and articles written for their local newsletters or online blogs. Presentations at seminars or conferences would have been another means to access a range of different audiences. The author is currently considering writing a paper based on this research for publication in a book and/or practice journal.

CREDIBILITY

The multiple case study method used for the research reported in Report 3 satisfies the criteria for making the rationale for case selection clear and transparent. The use of video alongside written analysis of interview material also makes the process of this study both transparent and accessible. However, not all of the individual cases were examined in sufficient depth through the full triangulation of data sources; a couple of them were hampered by the time that had elapsed since the research took place, resulting in an inability to make contact with all of the relevant stakeholders. The report and case studies would have benefited from an improved range and use of data sources (Hyett et al, 2014, p.8).

Changing Our Worlds achieved credibility amongst the communities of service user and survivor researchers, through foregrounding the often neglected field of user-controlled research (it is referenced favourably by Fleming et al, 2014; Boxall and Beresford, 2013; Beresford and Croft, 2012). It was widely distributed through the Shaping Our Lives website and networks (as well as through INVOLVE) which enabled it to reach a wider audience of service users and carers.

RIGOUR

As with other qualitative methods, case study methodology has been criticised as lacking in rigour and for its failure to produce generalisable findings (Yin, 2009; Hyett et al, 2014). As an investigation of a single or collective case, the aim of case study research is to capture the complexity of something that exists in particular circumstances. For case study research to develop and to contribute to the field of qualitative inquiry, Hyett et al (2014) suggest that its methodological credibility needs to be considered. In their view, this means giving sufficient detail for the reader to understand the study design and sufficient rationale behind key methodological decisions. The rationale behind case selection must be made clear and a wide range of data sources consulted for the adequate exploration of the whole case in its entirety (Hyett et al, 2014).

Report 3 demonstrated rigour in three main ways. Firstly, the deliberate and participatory selection of the case studies rendered the rationale for selection both systematic and transparent (Hyett et al, 2014); see section 2.3.2. The collection of the data was carried out in a participatory manner, including video recording of interviews, with the written summaries checked back with all participants. Full informed consent was obtained by the film-makers for the recording and use of video material. The first draft of each written example was sent back to the project participants to check for accuracy; amendments were made accordingly in line with principles of 'respondent validation' (Lewis et al, 2014; Lincoln and Guba, 1985). They were also given the opportunity to review and comment on the full report prior to publication. Thirdly, rigour was achieved through the inclusion of a passage of reflexive writing by the report author, as well as encouraging reflexivity on the part of the authors of the individual case studies. This process ensured that the perspective of the researcher in relation to the study was rendered transparent, as were the perspectives of the individual case study researchers.

Despite a transparent participatory approach, including validation of the findings with both the INVOLVE project advisory group and the participants, the report does not make clear the transition from the raw interview data through the analysis to the emerging themes and conclusions, which detracts from the credibility and perceived quality of the research (Spencer and Ritchie, 2014). Although this is relatively common in research carried out for

voluntary sector (as opposed to academic) organisations, this issue is of some concern to the reputation of this kind of research.

3.7 REVIEW PAPERS: PAPER 4 AND PAPER 10

Two of the papers in this thesis do not describe a conventional research methodology.

Paper 4 (co-authored with Rosemary Telford) reviews the learning about user involvement in mental health research through reference to literature, policy and practice. Paper 10 addresses service user experiences of acute mental health care with reference to the author's personal experience. Both of these papers benefit from being examined in relation to Pawson's TAPUPAS appraisal framework (Pawson et al, 2003) as outlined in 3.1. TAPUPAS asks questions of papers as follows:

- **Transparency** - are the reasons for it clear?
- **Accuracy** - is it honestly based on relevant evidence?
- **Purposivity** - is the method used suitable for the aims of the work?
- **Utility** - does it provide answers to the questions it set?
- **Propriety** - is it legal and ethical?
- **Accessibility** - can you understand it?
- **Specificity** - does it meet the quality standards already used for this type of knowledge?

PAPER 4: LEARNING ABOUT SERVICE USER INVOLVEMENT IN MENTAL HEALTH RESEARCH.

The aim of paper 4 (Telford and Faulkner, 2004) was to explore the learning to date about service user involvement in mental health research, through an examination of the relevant literature and policy context and through the experiences of service users and practitioners. It was not a systematic review and reflects subjective views but was a good example of co-production in joint authorship. The paper draws upon three complementary sources of knowledge and does so explicitly. It demonstrates transparency and purposivity: the method is appropriate for the aim of understanding service user involvement in mental health research, in that a range of sources of knowledge (theory and experience from the perspectives of a researcher and service user researcher) are explored. It demonstrates utility in that it answers the questions that it sets and accessibility in that it is entirely

readable; however, as it was intended for a primarily academic audience, it may not be accessible to a wider audience of service users who might be interested in the findings.

The paper concludes that, for service user involvement in mental health research to become more widespread, the potential contribution of the alternative (grey) literature needs to be acknowledged, alongside a willingness to challenge traditional research ideologies and processes. The authors advocate the establishment of common ground between researchers and service users for the development of shared research goals as a basis for successful collaboration. The paper has received 87 citations to date. A recent editorial addressing mental health strategy in Europe quoted this paper in relation to a discussion on barriers to public involvement in research (Callard & Rose, 2012).

PAPER 10: INSTITUTIONAL CONFLICT: THE STATE OF PLAY IN ADULT ACUTE PSYCHIATRIC WARDS.

Paper 10 starts by reviewing the findings of three recent reports on inpatient care: by the Sainsbury Centre for Mental Health (2005); the Royal College of Psychiatrists (2005) and mental health charity Mind (2004), with reference to a fourth (the King's Fund Inquiry into London's mental health services - Levinson et al, 2003). The paper then proceeds to explore the author's (my) personal experiences as an inpatient alongside the findings of these reports, thereby providing an analysis of different sources of data or information that centre on the theme of inpatient care.

Using the criteria from the TAPUPAS framework, the paper is transparent in that the author is clearly positioned in relation to the reports. It is accessible in that it is written clearly and is placed in a journal that reaches a practice audience, which means that the audience is relevant to the potential impact of the paper. This also speaks to the utility of the work; it answers the questions that it sets within the context given. It is difficult to assess the accuracy of the work other than to assert its accuracy from an authorial perspective. The use of examples aids in this process, but it is ultimately, in part at least, a personal perspective.

The paper draws on two substantial and contrasting sources of knowledge and employs a reflexive approach to the experience of inpatient care couched in the context of the findings of survey reports. The value of the article is that the personal narrative is used to illustrate (or give voice to) the personal experience of issues highlighted in the reports. The picture

that is drawn moves from the general and contextual knowledge-base to the perspective of personal experience.

The perspective (or standpoint) is explicit and transparent leading to a deeper exploration of the inpatient experience than would be feasible through an analysis of the reports alone.

Methodologically, this begins to move into autoethnography: a form of self-reflective writing that explores the researcher's personal experience and connects this autobiographical story to wider cultural, political, and social meanings and understandings (Ellis et al, 2011). Carr (2013) explores the value of autoethnographic methodology in survivor research as a 'framework for silenced voices and untold stories' (p.142). In essence, this approach uses the 'insider's' experience to give voice to those who are marginalised and silenced as a balance to the 'outsider' knowledge presented, in this case, in the survey reports. Whilst, for the most part, the two sources of knowledge are complementary, the personal experiences highlight the potential for staff to be the source of threatening behaviour, thus giving voice to potentially untold stories. For Ellis et al (2011) this paper would represent a 'layered account' of autoethnography where the author's experience is set 'alongside data, abstract analysis and relevant literature' (Ellis et al, 2011, p.6).

Significantly, Ellis et al (ibid) state that the autoethnographer, through producing accessible texts, aims to 'reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people.' (Ellis et al, 2011, p.3). This is highly relevant for the emancipatory purpose of survivor research: making experiential knowledge accessible to the wider community of service users and survivors, putting that knowledge at their disposal.

There is the danger, as pointed out by Carr (2013, p.140) and Humphries (2000b) of sliding from autoethnography (or reflexivity) into 'self-indulgence'. This highlights the importance of both relevance and context: the transparency, accuracy and purposivity of the TAPUPAS framework (Pawson et al, 2003) as demonstrated by this paper. The paper is also clear (accessible) and transparent about the perspective and its approach. Taking an individual and personal experience is always open to criticism by virtue of being idiosyncratic and unrepresentative of a wider population, in this case of adults experiencing inpatient care. However, the placing of the individual experience in the context of a series of reports on

inpatient care and their complementary findings, gives both a wider context for the individual experience and greater credibility for both.

I had not come across the term 'autoethnography' prior to undertaking the work for this thesis and, having read more about this approach (Carr, 2013; Ellis et al, 2011; Fabris, 2012; Short et al, 2013), I feel I would take the analysis of the two sources of knowledge further if writing the article now, developing the analysis of my personal experiences with greater confidence and consequently achieving a more comprehensive and in-depth analysis of the issues addressed in this paper.

CHAPTER FOUR: THE CONTRIBUTION OF THIS BODY OF WORK TO MENTAL HEALTH KNOWLEDGE AND RESEARCH

In this chapter I draw this thesis to a conclusion by identifying the contribution made by the publications submitted in this thesis to mental health and survivor knowledge and knowledge production under four headings. I then consider the impact of the work on mental health research, before addressing the role and value of experiential knowledge within the context of these publications and the theoretical underpinnings. Finally I reflect upon my development as a researcher and the experience of undertaking this PhD.

4.1 THE CONTRIBUTION OF THIS BODY OF WORK

In this section I argue that the ten collected pieces of work contribute to a growing knowledge base in mental health that originates from service users and survivors: that this experiential knowledge constitutes a valid and significant challenge to mainstream mental health knowledge and research (Beresford, 2005; Beresford and Boxall, 2013; Sweeney, 2013; Rose, 2008). This contribution is addressed in this chapter under the following four headings:

- Service users as researchers and 'knowers'
- Critical perspectives on mainstream mental health services and treatments
- The role of identity and power
- The significance of relationship and connectedness

4.1.1 SERVICE USERS AS RESEARCHERS AND 'KNOWERS'

The central argument of this thesis is that this body of knowledge represents both a contribution and a challenge to mainstream mental health knowledge and to mental health research. The two are inevitably intimately connected. At the core of this is the development of service users and survivors as researchers and as 'knowers' of mental health knowledge: the knowers of mental distress, of mental health services and of their discriminated status within society (Wallcraft, 2009; Rose, 2008; Radden, 2012; Russo and Beresford, 2014; Costa et al, 2012). The work contributes to the challenges made by wider communities of service users and survivors to mainstream mental health services and mental health research, challenges addressing the medicalisation of distress and the

exclusion of service user narratives and the service user voice (Armes, 2009; Sweeney, 2009, 2013; Rose, 2008; Morgan et al, 2016).

Survivor research has the capacity to highlight the realities of living with mental distress within a society that does not value that experience. It does this by asking different questions based on lived experience (Faulkner, 2004a), but also by closing the distance between the researcher and the researched, challenging the means by which knowledge is produced (Boxall and Beresford, 2013; Barnes, 2003) and demonstrating emancipatory purpose (Beresford and Rose, 2009; Sweeney, 2009). Perhaps most of all it does this by listening to the testimonies or narratives of service users and survivors (Rose, 2008; Morgan et al, 2016).

The Strategies for Living research (Report 1) was one of the first pieces of user-led research in the UK to demonstrate both the capacity of mental health service users/survivors to be researchers and to demonstrate the value of undertaking research from a survivor perspective. As stated in 3.2, the research has been described as 'groundbreaking' and as one of the two major programmes of research to establish survivor research in the UK (Sweeney, 2009). Strategies for Living originated out of a service user/survivor knowledge base with the aim of demonstrating 'emancipatory purpose' (Tew et al, 2006). It has also contributed to the growing sense of a service user/survivor movement:

‘One of the most important progressions which have drawn people in [to the user/survivor movement] is the growth of self-management, like the Strategies for Living project, approaches developed by the Hearing Voices Network, the National Self-Harm Network, the Manic Depression Fellowship. When we develop our own frame of reference, this takes us away from the debate about whether services are shit or not and what do we do about them. I think that has really drawn people in because people have a chance to use their expertise...’ service user quoted in Wallcraft et al (2003, p.13)

Reflections by the service user researchers and interviewers in this research began to develop our understandings, both of the significance of the findings and of the role of user-led or survivor research in creating mental health knowledge (Russo, 2012; Costa et al, 2012). We explored our shared understanding of what it meant to experience both distress

and discrimination and to use this knowledge to carry out research that could be meaningful to the wider community of people experiencing distress, service users and survivors (Tew et al, 2006; Faulkner, 2004a). Perhaps the most significant message of this project was simply that mental health service users *could* – and can – carry out good quality research and explore issues relevant to ourselves and our communities.

Learning the Lessons (Report 2, Papers 5 and 6), taking place a few years later, made a significant contribution to our understanding of how 'user involvement' in research can be undertaken (Sweeney and Morgan, 2009; Turner and Beresford, 2005; Russo, 2012). The module undertaken by myself and colleagues was 'user-led' in that it was undertaken autonomously by service user researchers, within and alongside the larger programme of research led by clinical academics to evaluate the services for people diagnosed with personality disorder. In both this research and Strategies for Living, people with experience of mental distress and of using mental health services gained research skills and knowledge during the course of the research, through training and through the experience of interviewing their peers. This is one of the key issues raised by Jones and Brown (2013) in their discussion about the need for more service user/survivor autonomy and control in mental health research:

'Users and survivors of the mental health system ... must be allowed to take on leading roles in both the generation and dissemination of scientific knowledge.'
(Jones and Brown, 2013, p.1)

In Paper 6 (from Learning the Lessons) we concluded that service users/survivors could play a major role in carrying out research from design and development through delivery, analysis and report writing. The role of service users as interviewers may have invited different responses to these questions; certainly the questions themselves were determined in part by the service user research team. Without a direct comparison of service user researchers versus academic researchers as interviewers, it would be impossible to be sure about this. However, it was the view of the team as a whole (as discussed in Paper 6) that the process enabled service users to speak more openly and honestly about their experiences. Themes that arose in this regard included mixed views and feelings about the personality disorder diagnosis; some traumatic experiences of the lengthy assessment

procedures; an appreciation of peer support when it was an option; and criticisms of the lack of flexibility in therapeutic model and approach.

The issue of service users as interviewers has been explored by a number of survivor researchers and others, many of whom share the view that service user interviewers can elicit more open and honest answers and obtain more in-depth information, particularly where services themselves are under examination (Gillard et al, 2010; Gillard and Stacey, 2005; Faulkner, 2006; Rose, 2003b; 2004; Clark, 1999).

Overall, the Learning the Lessons study contributed significantly to the body of knowledge constituting 'user involvement in research', particularly in relation to the value of being involved in the analysis as well as the interviewing; we felt that this both added to our own learning and ensured an extra level of validity to the findings (see also Allam et al, 2004). At the time, this was rare amongst collaborative research projects (Minogue et al, 2005; Staley, 2009) so this study was pushing the boundaries of what was conventionally understood to be 'user involvement in research' and once again, enabling or promoting the idea that service users could become the 'knowers' of their(our) own lives and experiences. The little evidence there is about this suggests that involvement in the analysis and/or interpretation of results gives service users a greater sense of ownership of the research (Staley, 2009).

This positioning of service users as the 'knowers' is also relevant in relation to the peer support papers (Paper 7 and 8). These two papers were innovative in highlighting the significant role of peer support in the lives of many people living with mental distress, emphasising that the existence of peer support in mental health long pre-dated the introduction of 'intentional peer support' (or IPS) as a form of intervention in mental health services. These papers, in effect, were part of the process of reclaiming peer support for the UK service user/survivor movement from its co-optation by mental health services (Penney and Prescott, 2016).

Both Report 3 (Changing Our Worlds) and the individual case studies covered within it also convey the significance of service users and disabled people becoming the 'knowers' of their own worlds. Report 3 made a significant contribution through placing 'user-controlled research' firmly on the agenda, both for service users and disabled people and for the wider community of researchers reached through the funding organisation INVOLVE, whose

primary focus was - and is - on public involvement in research. User-controlled research is featured on the NIHR INVOLVE website, with this report and the accompanying film alongside reports by Turner and Beresford (2005) and Beresford and Croft (2012).

4.1.2 CRITICAL PERSPECTIVES ON MAINSTREAM MENTAL HEALTH SERVICES AND TREATMENTS

One of the fundamental features of survivor research is that it does not accept a biomedical paradigm as given (Beresford and Wallcraft, 1997; Sweeney, 2016) and gives space for the consideration of alternative understandings and social and political factors often not taken into account by traditional mental health services or research. The foregrounding of service user perspectives opens up the space for significant critiques of mainstream services and treatments, as is reflected in some of the early user groups and organisations such as Survivors Speak Out, the National Self-Harm Network, the Hearing Voices Network and the UK Advocacy Network (for example: Pembroke, 1994, 1996; Harmless, 2009). Each of these highlighted shortcomings in the way services dealt with specific issues, such as self-harm and eating distress, as well as campaigning for greater access to advocacy and alternatives to hospital in a crisis.

Within the context of this thesis, the nature of this new space ranges from the Strategies for Living research (Report 1) which took the approach of putting services in their place alongside the role of other sources of support in people's lives, to Paper 10 where the critique of inpatient services is both more personal and more direct.

The Strategies for Living research invited people to talk freely about whatever they found helpful in their lives, without starting from a biomedical paradigm or from a service-based standpoint. The result was that people primarily talked about sources of support outside mainstream mental health services. Whilst relationships played a significant role, so also did factors such as: religious and spiritual beliefs, physical exercise, personal strategies such as taking control and finding peace, a stable and secure home, information and a variety of hobbies and creative activities. Underlying these strategies were themes of acceptance and belonging, finding meaning and purpose, and the importance of taking control and having choices, themes rarely addressed in mainstream services, until perhaps the introduction of the Recovery approach (Repper and Perkins, 2003; Shepherd et al, 2008).

In a similar vein, the papers addressing peer support (Papers 7 and 8) explored the role of peer relationships and support gained through connection with others, usually but not exclusively outside of mainstream services. The benefits of peer support included: having a shared identity, reduced isolation; increased self-confidence; the opportunity to help others; developing and sharing skills; improved mental health and wellbeing; information and signposting; challenging stigma and discrimination. What is innovative about these two papers is that they highlight the fundamental distinction between peer support as shared ethos and foundation of a social movement (Emerick, 1996) and peer support as a form of service delivery or intervention (Gillard et al, 2013; Simpson et al, 2014). This issue is well articulated by Penney and Prescott (2016) who describe the establishment of grassroots peer support in the U.S. being usurped by the increasing development of peer specialist roles within mental health services in the 1990s, essentially conflating 'peer support' with the peer staff model, 'implying that any service provided by a 'qualified peer support provider' was, by definition, 'peer support' (Penney and Prescott, 2016, p.40).

Paper 9 made a significant contribution to our understanding of risk through challenging traditional (administrative, service-based) notions of risk, in this way demonstrating the value of being able to step outside of the conventional paradigm. Services themselves come under scrutiny as a source of risk, loss of control and loss of independence in a risk-averse culture (Carr, 2010; Wallcraft and Sweeney, 2011). Research and policy regarding risk has tended to reflect an exclusively professional or organisational/administrative agenda (Carr, 2010; Wallcraft and Sweeney, 2011). In recent work, it is clear that this bias is operationalised in practice, with practitioners rarely engaging service users in conversations about risk (Coffey et al, 2016). In a similar way, Paper 10 takes an innovative approach to looking at acute inpatient care through the eyes of the author-as-inpatient, alongside the analysis of a number of contemporaneous surveys and reports on inpatient services. This allows for a more direct and personal critique of services, set within the context of the evidence provided by national and local reports on inpatient services.

4.1.3 THE ROLE OF IDENTITY AND POWER

The body of work contained within this thesis highlights the profound significance of issues associated with identity and power for service users and survivors: in their lives, in relation to their experience of services and in relation to the research itself (Faulkner, 2016). These

issues are rarely identified or explored within mainstream research. As explored in Chapter One, being given a mental illness diagnosis results in a 'spoiled identity' with potentially devastating effects on people's lives, relationships and rights to equal citizenship (Goffman, 1963). The effects of this emerge in different ways from these publications, alongside the strategies people adopt to regain a stronger and/or different sense of identity (Brown and Kandirikirira, 2007; Morgan et al, 2016).

'Identity is important for mental health, as it bestows upon the bearer a sense of belonging with others who share similar experiences'. (Essien, 2009, p.63)

Identity and power come into play in relation to the identity of mental health service users/survivors being or becoming researchers. Engaging in research and forming a (new) identity as a researcher can lead to more power/empowerment, although this can be complex as old power relations can be reworked in new places (Rose, 2003b; Hutchinson and Lovell, 2012; Faulkner, 2016; Kalathil, 2013). Intersectional power issues can and do exist in survivor spaces too, and this is particularly the case for racialised groups, who are often excluded from 'involvement' initiatives as a result (Kalathil, 2011a; 2013). Equally, individuals gaining power through new expertise and identity can find themselves in difficult positions in relation to their erstwhile peers who may see them as role models and leaders, but also as professionals and no longer equal (Rose, 2003b; Faulkner, 2016). This issue certainly emerged in the interplay between the researchers and the researched explored in the case studies for Report 3, where identity is explored from the perspectives of the people carrying out the user-controlled research projects. They shared aspects of their identity with their research participants at the same time as moving beyond and away from them as they developed new identities as researchers.

In addition, the knowledge that we (as service users and survivors) produce and the research that we do has less power than that produced by clinical academics through positivist methods (and indeed non-positivist methods) (Fisher and Freshwater, 2014; Beresford and Boxall, 2013). This issue is highlighted by Report 4, which made a major contribution to the existing knowledge base through reviewing the current status of user involvement in mental health research from personal and professional perspectives alongside a review of the literature. Although this paper revealed increasing evidence of

service user involvement in peer-reviewed journals (since the review by Faulkner and Thomas, 2002), it also found a significant amount of material in the alternative or 'grey' literature produced by user-led and voluntary sector organisations. The authors conclude that researchers working in this field need to take into account the extensive literature that does not, or cannot, reach peer-reviewed journals if they are to fully appreciate the different perspectives offered by service users and survivor researchers.

This conclusion provides part of the justification for the publications in this thesis: several do not appear in peer-reviewed journals or appear in low impact practice-oriented journals (e.g. the Journal of Adult Protection; Mental Health and Social Inclusion). Service user and survivor researchers tend to be motivated by a commitment to change or improve services (Faulkner, 2004a) and hence seek audiences of frontline staff and service users, sometimes through practice-based journals or shorter accessible publications. They are less affected by the pressures that affect clinical academics, such as the need to fulfil the Research Excellence Framework (REF) or to generate income. There are additional biases in peer-reviewed journals that fail to appreciate qualitative research, research that challenges mainstream methodologies and ideologies, and research originating from service users and survivors (Sweeney, 2016; Glasby and Beresford, 2006). Consequently, power emerges as one of the themes to explain what is going on more broadly for this research, as well as something being played out quite directly, as in the case of the power relations between staff and patients on the wards explored in Paper 10.

Within the individual papers, a shared identity is often conceived of as a source of empowerment and as the basis from which to share experiences. Report 1 identified the value of shared experience and shared identity underlying the various 'strategies for living' with mental distress, alongside the need to achieve a sense of acceptance and belonging. Report 2 (with Papers 5 and 6) found that people diagnosed with a personality disorder held very mixed views, experiences and feelings about the diagnosis, often influenced by the implications it had held for accessing services, but also for the sense it conveyed of having a damaged personality or self/identity. They were also critical of services that maintained an inflexible approach and where rules or boundaries were both rigid and non-transparent, rendering the service users powerless to understand or negotiate them.

In Papers 7 and 8, the shared identity that underlies the core of peer support relationships is highlighted, with its role in reducing isolation, increasing self-confidence and wellbeing. Peer support is identified as a potential source of empowerment, from its starting point of shared (disempowered) experience and mutual support.

For Paper 9, the issue of power emerges in relation to the fear many people experienced of the disempowerment accompanying loss of independence, coupled with a fear of retribution if they attempted to stand up for their rights within a service setting. A fear of contact with services was expressed by some people with mental health problems, given their awareness of the potential of the Mental Health Act to remove their freedom and independence. These issues served to emphasise the role of power and empowerment for people in receipt of health and social care services, an issue once again experienced differentially, since racialised and other marginalised groups will experience greater discrimination and disempowerment than their (for example) white, male, heterosexual peers.

A key message from Paper 10 is the significant role of power in influencing the ward environment and people's experiences within it. The reports reviewed in this paper along with the personal experiences described both explore disempowering treatment. The personal experiences highlight incidents that demonstrate the feeling of disempowerment from the inpatient perspective. The paper highlights the role of power in institutional life, and the need for ways of dealing with complaints and abusive treatment on acute wards. Implications are drawn for adult safeguarding, which rarely takes account of people with mental health issues or the potential for abuse within mental health services.

4.1.4 THE SIGNIFICANCE OF RELATIONSHIP AND CONNECTEDNESS

This body of work highlights the significance of relationship and connectedness, not only in people's own lives and recovery, but as the foundation of experiential knowledge (see 4.3). Relationship is both the flipside to the discrimination and isolation that can be created by being diagnosed with a mental illness, and a key strategy for dealing with those challenges. The search for, and significance of, acceptance and belonging, the essence of relationship, runs through many of these publications. A significant contribution made through these publications is to highlight the significance of connecting through sharing our narratives in

peer relationships in the development of experiential knowledge, a theme that speaks to the heart of this thesis (Emerick, 1996; Noorani, 2013; Morgan et al, 2016).

'For one of the most vital ways we sustain ourselves is by building communities of resistance, places where we know we are not alone' (bell hooks, 2015, p.213).

One of the central findings of Report 1 (Strategies for Living) was that relationships of different kinds formed the most significant source of support in the lives of people living with mental distress. Some people talked of the transformative experience of meeting other people with similar experiences or diagnoses and the role of being able to share and connect with them. It is hard to fully articulate the significance of this. Diana Rose (2009), in writing about her early experiences of treatment for self-harm in A&E (being stitched without anaesthetic which she experienced as punishment), says that the 'scales really fell from my eyes'(p.171) when she heard a woman in a user group talking about the same experience and framing it as an injustice.

The central role given to relationships does present a very different picture of the lives of people living with mental distress to that often presented by mainstream mental health research and services (Gilburt et al, 2008). The significance of relationships to people living with mental distress is rarely given the degree of emphasis it deserves; just recently it has been referred to as 'the forgotten foundation of mental health and wellbeing' (Mental Health Foundation, 2016). Some clinical academic researchers have recently begun to focus on the importance of social networks, albeit from a broadly positivist perspective (Siette et al, 2015; Anderson et al, 2015), even advocating that psychiatry embrace the social perspective as central (Priebe et al, 2013).

The Learning the Lessons research (Report 2, Papers 5 and 6) identified relationships and peer support as service features appreciated by the people using the community-based services for people with a diagnosis of personality disorder. Paper 9 (on risk) identified the significant role of trusting relationships in connection with the experience of managing risk. Close trusting relationships could be the key to greater independence and choice, enabling people to take positive risks with a greater degree of confidence. Equally, some unequal relationships (for example with care-givers in early or later life) could be over-protective and

risk averse, preventing people from taking positive risks and from being as fully independent as they could be.

The significance of the underlying themes of acceptance and a sense of belonging, shared experience and shared identity, identified in the Strategies for Living research, also form the basis for the exploration of peer relationships and peer support that takes place in Papers 7 and 8. The sense of connectedness felt through shared experience and shared identity create the foundations for both 'peer support' and the experiential knowledge that emerges from it (see 4.3).

Paper 7 explores these changing meanings associated with 'peer support' taking place largely within the 21st Century. Key findings from this paper concern the differences in approach, delivery and attitudes to peer support identified within different service user and peer support groups. Although there were shared benefits and challenges across the different groups, there was a clear difference in ethos and intent between service user groups in existence prior to the development of intentional peer support (IPS) and those engaged primarily in IPS.

Building on Paper 7, Paper 8 explores the potential for the 'professionalisation' of intentional peer support to endanger the mutuality and equality that lies at the heart of peer support relationships (Noorani, 2013; Penney and Prescott, 2016) and hence to weaken the foundations of experiential knowledge. During the period in which the body of work covered in this thesis was being undertaken, 'peer support' in mental health developed a new identity, becoming both a recognised source of support and a new intervention (Simpson et al, 2014; Gillard et al, 2013). Whilst the former could be seen as a positive outcome of the efforts of the service user and survivor movement, the latter demonstrates how such a development can be co-opted and professionalised by policy and service development initiatives (Penney and Prescott, 2016).

The significance of being able to share experiences, to find the spaces in which to build relationship and connectedness, speaks to the heart of how we form experiential knowledge; this notion is further developed in 4.3.

4.2 IMPACT AND RESEARCH

In this section I address the question of impact and research: what impact has this body of work had on mental health research, and what is the relationship between the degree of involvement or control over research exercised by service users/survivors and the impact the work has achieved. In conventional impact terms, the author's H index as calculated by Google Scholar is given as 20 with total citations at 1423; with two of the publications in the PhD listed as having around 100 citations (Report 1 - 194 and Paper 4 - 86).

The pieces of work in this thesis lie at different places along a proposed continuum of service user or survivor 'involvement' in research (Sweeney and Morgan, 2009), which runs from consultation through contribution and involvement to collaboration and control. At the 'control' end are Report 1 and Papers 7, 8, 9 and 10 (Strategies for Living; peer support papers; risk paper; acute care paper). Paper 4 was collaborative. Report 2 with papers 5 and 6 might be conceived of as 'involvement in research' but the definition is hard to nail as the individual module was strongly user-led. Equally, Report 3 was a hybrid of collaboration and user-led research, with collaboration between myself and the INVOLVE staff team, but with considerable freedom to identify and analyse the issues relevant to user-controlled research.

During the course of the work represented in this thesis, the UK research context has changed significantly. There has been a shift towards requiring the involvement of service users and carers (or 'members of the public') in publicly funded research through the Department of Health National Institute for Health Research (NIHR) and the Medical Research Council amongst others (Rose, 2014b). The body of work in this thesis has made a major contribution to these changes. The author was a member of the NIHR INVOLVE Advisory Group for several years as a direct result of the Strategies for Living research (Report 1) and my work continues to be featured on the INVOLVE website. I was involved in the early days of developing guidance for service user involvement in the Mental Health Research Network, a NIHR network that no longer exists but which supported a specific service user and carer hub during its lifetime (Service User Research Group England, 2005).

However, the degree to which this kind of involvement in research can have impact remains in some doubt (Crocker et al, 2016; Rose, 2014b; Minogue et al, 2005). Staley (2009),

exploring impact for NIHR INVOLVE, identified that public involvement in research could have an impact on a number of areas. She found that it could increase recruitment to research; that it was of particular value in qualitative research where participants are asked to share their views and experiences; that it was of value in clinical trials where it helped to improve trial design and use of relevant outcome measures; and that it benefited both research participants and those involved. A significant difficulty is the under-reporting of involvement in publicly accessible documents, leading to poor evidence of impact (Staley, 2009; Wilson et al, 2015). A systematic review of the impact of PPI (Brett et al, 2012) found a similarly thin evidence trail, although they did conclude that involvement can have positive impact on research, enhancing the quality of research and ensuring its appropriateness and relevance to end users.

Many service user and survivor authors have raised concerns about potential tokenism and the possibility of service user/survivor researchers (and their knowledges) being co-opted by the more powerful agenda of clinical academic researchers (Russo, 2012; Beresford, 2005; Faulkner, 2004a). Research that involves service users but is undertaken from a clinical academic standpoint tends to be interested in the views of service users as one of a number of sources of data; there is little or no opportunity to challenge pre-existing paradigms of knowledge or methodology (Beresford and Boxall, 2013; Russo, 2012). This is certainly true to some extent of Report 2, Papers 5 and 6 (Learning the Lessons evaluation). Underlying the main body of this research was an acceptance of the existence of the diagnostic framework and of 'personality disorder' in particular: this was non-negotiable. However, within that framework, a significant degree of autonomy was achieved, partly through locating the user-led module within the voluntary sector. The findings appear to have been taken up by statutory services and referenced within practitioner manuals (for example, Bolton et al, 2014, produced by NHS England in collaboration with the user-led organisation Emergence).

In this sense, the question about impact becomes more complex. Research funded and taking place within a statutory service context might have greater impact on mental health services, but equally academic research itself often struggles to have a direct impact on patient outcomes (Greenhalgh and Fahy, 2015). Research impact can be measured in citation terms but whether it has an impact on patient experience is less clear. The recent

moves to develop structures to support implementation research are intended to improve this relationship: 'CLAHRCs are collaborative partnerships between a university and the surrounding NHS organisations, focused on improving patient outcomes through the conduct and application of applied health research' www.clahrcprojects.co.uk.

Nevertheless, the prevailing rhetoric in the health research world as a whole is that of user or public involvement, with an underlying consumerist ideology 'that is not necessarily consistent with, or supportive of, the inclusion and development of experiential knowledge' (Beresford and Boxall, 2013, p.74). By becoming involved in clinical academic research, we may compromise our priorities for research and can be said to support the biomedical model. By standing resolutely outside and seeking to develop independent user-controlled research, we have less access to funds and a lesser potential to impact on services.

Whilst the funders and initiators of research have the greatest power over the nature and direction of research, organisations independent of mental health services and mainstream research funding can produce research less tethered to mainstream theories and ideologies (Beresford and Boxall, 2013). Much of the research represented in this thesis took place within the voluntary sector with some of the freedoms afforded by this independence to benefit it: the opportunity to undertake user-controlled research, coupled with the freedom to ask different questions and challenge traditional research methods. However, the resources for such research are increasingly thin on the ground, resulting in smaller projects less likely to be published in peer-reviewed journals.

As with clinical academic research, research taking place within user-led organisations or the mental health voluntary sector is more likely to have an impact within its own sector: on voluntary sector policy, campaigning and services. As an example, the peer support research represented by Papers 7 and 8 had an impact within the voluntary sector policy and provision of peer support (for example, of the organisations MIND and Together for Mental Wellbeing) but not on the continuing development of intentional peer support in statutory services. Report 1 (Strategies for Living) was unique among this collection in having a fairly comprehensive spread of impact, but almost certainly developed its greatest credibility and influence within the service user/survivor communities and mental health voluntary sector. This was partly aided by the nature and amount of funding from the National Lottery and

the commitment of the team to remaining grounded in grassroots service user activism and knowledge.

4.3 THE ROLE AND VALUE OF EXPERIENTIAL KNOWLEDGE

Experiential knowledge and the means of expressing, sharing and collectivising it, runs through all of the pieces of work gathered in this thesis. As mentioned in Chapter One, Sweeney (2013) sees experiential knowledge as the bedrock of survivor research, a perspective shared by many other survivor researchers (Russo, 2012; Beresford, 2005; Rose, 2009; Sweeney, 2013; Kalathil, 2011b). It is my contention that experiential knowledge emerges from our relationship and connectedness: from the peer support and self help spaces that we (as service users and survivors) find and create (Emerick, 1996; Wallcraft et al, 2003; Noorani, 2013), whether it be through sharing our knowledge of distress and self-care/self-help, our experience of using (or not using) services, or of being subject to stigma, discrimination and abuse. This is the thread that runs through the works in this thesis.

Our voices are largely silenced by mainstream mental health services and research intent on understanding how to reduce or remove symptoms or comply with treatments/services. We are written about and talked about, treated, measured and counted, but mostly remain silent and silenced about our experiences of mental distress and of using services - particularly in relation to published work. '...historically, our experiences have been disbelieved or dismissed, while our distress has been reduced to symptoms of psychiatric conditions' (Sweeney, 2013, p.5). We rarely have the chance to give voice to our experiences on our own terms - without pre-conceived notions of what we can or should talk about constructed by professionals or researchers. It is the role of survivor research to open up new spaces for people to share their experiences and build from the individual story to a body of collective knowledge(s) (Carr, 2013; Rose, 2008; Beresford and Boxall, 2013) as exemplified by Report 1 and Papers 7 and 8.

As stated earlier in 1.1, this knowledge has the potential to develop its own 'experiential authority' (Noorani, 2013; Borkman, 1990) capable of questioning the adequacy and effectiveness of professional knowledge or practices. For Noorani, this experiential authority is gained through the active process of 'living with and working through a mental distress' (p.61) in peer support/self-help groups at the same time as passing down knowledge

through the successive generations of group/space participants. The permission to hold or possess authority given through relationships of trust and knowledge is both broadened and deepened through the sharing of different stories. Both Noorani (2013) and Borkman (1990) emphasise the importance of working on and through techniques and strategies over time, through a process of sharing stories. So, the individual story becomes the foundation stone of peer-developed and peer-shared knowledge in 'experiential learning communities' (Borkman, 1990) or self-help/peer support groups and user groups.

Like Emerick (1996) and Noorani (2013), I believe that peer support/self-help spaces can be radical and transformative, the foundations of our social movement. In the seminal work 'On Our Own Terms' which surveyed the existence and activities of service user groups, Wallcraft et al (2003) described the 'service user/survivor movement' as

'the existence of numerous individuals who speak out for their own rights and those of others, and local groups and national organisations set up to provide mutual support or to promote the rights of current and former mental health service users to have a voice.' Wallcraft et al (2003, p.3)

Research does not obviate the need for these 'experiential learning communities', although it can perhaps short-circuit the process of achieving 'experiential authority' - as in the case of Report 1 which was part of a programme of work connected to wider networks of service user and survivor communities. As Rose (2008) describes, research is one way of 'systematically collecting user testimonies' to confront mainstream psychiatry with the 'flaws in its own research and practice' (p.643). Equally, the many groups identified by Wallcraft et al (2003) are providing the spaces for mutual (peer) support and for experiential knowledge to develop authority locally.

The independence and the values of service user-led (peer-led) peer support are likely to be compromised if peer support continues to be incorporated as an intervention by mainstream services (Penney and Prescott, 2016). Whilst an individual and personalised model of peer support as a means of providing services has many strengths, there is a risk that in supporting this, commissioners will direct funding away from service user groups where informal and group focused peer support takes place (Wallcraft et al, 2003) and where a social movement has its roots (Emerick, 1996). As an intervention, 'peer support'

will increasingly become time-limited, assessed and evaluated by measures inappropriate to the ethos of peer support (Penney and Prescott, 2016). Together with an increasingly neoliberal approach to services in which the individual is the focus of understanding cause and care, this has the potential to reduce the opportunities for people to meet together, support one another, plan and campaign independently of mainstream services. To take a step further, the potential risk here is to the service user/survivor movement itself since the movement relies upon the collective sharing of experiences and narratives (Emerick, 1996; Noorani, 2013; Morgan et al, 2016). Emerick contends that 'self-help can be, and is, a meaningful progressive civil rights and protest social movement' (Emerick, 1996, p.138).

The body of work in this thesis speaks to each of these levels of experiential knowledge development: knowledge of distress and self-care/self-help (Report 1, Paper 9), knowledge of services (Report 2, Papers 5 and 6, Paper 10), and the process of collectivising and sharing experiential knowledge and developing 'experiential authority' (all to some extent, but particularly Reports 1 and 3, Paper 4, Papers 7 and 8). The journey that takes place is from individual stories to ways and means of sharing those stories, to building experiential knowledge that gains 'experiential authority' through research and through the development of 'experiential learning communities'. In a sense it is an interconnected cycle of learning and sharing; the individual story should never be entirely lost from the process as the development of experiential knowledge and authority takes place. Neither survivor research nor the new and emerging discipline of 'Mad Studies' (LeFrancois et al, 2013; Russo and Beresford, 2014) can afford to lose contact with our variety of mad communities or our individual stories if they are to retain credibility with those communities and sustain the trust that supports the development of experiential knowledge (Russo, 2016; Jones and Brown, 2013).

4.3.1 THEORETICAL UNDERPINNINGS

As outlined in Chapter One, standpoint theory has much to offer to our understanding and to the situating of survivor knowledges. Standpoint theory offers us another way of positioning the knowledge that originates from different (marginalised) sources (Harding, 1993); it enables us to understand that the knowledge gained from the experience of people deemed mentally ill is not, by its very nature, invalid or somehow deviating from an assumed perspective or 'truth'. It empowers the voices of those less powerful and validates

the significance of their experience. Wood (2009) states that a standpoint is 'earned through critical reflection on power relations and through engaging in the struggle required to construct an oppositional stance' (p.61). This is not dissimilar from the arguments made earlier about the development of experiential authority out of experiential knowledge (Noorani, 2013). It is also allied with the conceptualisation of standpoint by Collins (2009) as founded on group-based and historically shared experiences. In other words, it is not an individual standpoint but a shared standpoint as experienced through membership of an oppressed group or groups. She, amongst others, reminds us that there is little value in a singular standpoint (or identity) but that we need to remember the 'inconvenient complications' of our different identities (Jones and Kelly, 2015).

Rose (2014b) points out that standpoint theorists 'have not explicitly theorised knowledge production among those with long-term health conditions, but it can be argued that the model is transferable' (p.155). Kokushkin (2014) similarly proposes that 'fields dominated by positivist thinking would benefit from implementing standpoint approaches as means to destabilising the existing orthodoxies and creating alternative knowledges' (p.15); that people working in a range of fields could use standpoint theory to reclaim knowledge based on their group's experiences. He suggests that standpoint theory can be used to validate the empowerment of perspectives 'traditionally ignored or excluded from the production of knowledge' (Kokushkin, 2014 p.15). This helps to contextualise the body of work in this thesis through validating the notion of starting from an explicit service user perspective and locating this within the field of mental health knowledge, which is indeed dominated by positivist thinking.

Alongside standpoint theory, there remains a significant place for the emancipatory research paradigm in understanding the contribution of the works in this thesis (Tew et al, 2006; Boxall and Beresford, 2013; Beresford and Rose, 2009). Standpoint theory has been accused of being relativist, whereas the emancipatory paradigm may be seen as more explicitly political. As stated in Chapter One, emancipatory research incorporates the notion of accountability to communities of, in this case, survivors and is 'openly partisan' (Boxall and Beresford, 2013). The purpose of the research is essentially liberatory and challenges the academic or professional knowledge inherent in mainstream research.

4.3.2 MAINSTREAM MENTAL HEALTH KNOWLEDGE AND RESEARCH: THE CONTEXT

In order to appreciate the role and value of experiential knowledge, it is important to consider the context within which it is produced and considered. What is considered to be 'true' knowledge is influenced by the power relations in our society and culture. Professional knowledge, gained through education and learning, has a higher status than 'experiential' knowledge thus shaping mental health research and services in its image (Boxall and Beresford, 2013). As a result, the dominant paradigm in mental health reflects the professional model predicated on the existence of mental illness as a set of diseases with biomedical origins (the 'biomedical' model). As stated in 1.1, this 'modernist' framework (Bracken et al, 2012) has resulted in an emphasis on technical expertise and the use of an individualist framework that 'marginalises the lived experience and knowledge of those deemed mad.' (Coles et al, 2013, p.vii).

Whilst referring to the biomedical model in these terms may at first seem reductionist and that psychiatry would better be described as using a bio-psycho-social model, it remains the case that clinical academic researchers return to their biomedical roots when designing clinical trials, investigating treatments and causes on a strictly defined diagnostic basis in order to maximise methodological effectiveness (Faulkner, 2015). Also, even when social and psychological factors are acknowledged as part of the picture, they are frequently given lip service and are certainly given a small fraction of the research funding available: the main business of clinical mental health research remains biomedicine (Beresford and Menzies, 2014).

Of particular relevance to the power/knowledge relationship in mental health is Foucault's assertion that the history of psychiatry is a 'monologue of reason about unreason' (Foucault, 1971, xii-xiii quoted in Morgan et al, 2016); in other words the dominant discourse has been shaped by those people who can lay claim to 'reason' which, by implication, the mentally ill or mad cannot. This dilemma continues to be played out to this day (for example, Rose, 2003a; Sweeney, 2016).

There is an intimate relationship between the dominance of the biomedical model and the dominance of positivist methods used to evaluate interventions within evidence-based medicine (EBM) (Faulkner and Thomas, 2002). They presuppose that it is possible to

measure mental illness accurately, which it is not; as pointed out by Middleton (2013) and Thomas (2013) amongst others, diagnoses are unstable and of limited value to research or clinical practice. The production of experiential knowledge does not sit comfortably with traditional positivist methodology (Beresford and Boxall, 2013; Fisher and Freshwater, 2014). The interventions given legitimacy by clinicians and by NICE (the National Institute for Health and Care Excellence) are those that have been tested using randomised controlled trials (RCTs). There is more 'good quality' research evidence about medication and other interventions that can be more easily tested through positivist methods, thus perpetuating the dominance of the medical model within psychiatric care in a kind of virtuous circle.

Reliance on positivist methods for best evidence continues to undervalue any intervention for which the outcomes are difficult to measure (Petrie, 1998), and this has limiting effects on the nature of the knowledge and evidence produced (Beresford, 2010; Sweeney, 2013; Rose, 2009). First person experiences and small-scale qualitative studies are devalued in relation to the notion of 'objective' evidence produced through clinical trials (Beresford, 2016). Clinical trials of peer support are a case in point: assessed on the basis of inappropriate outcome measures such as hospital admission and symptoms, when the impact of peer support on such aspects as hope, recovery and empowerment is largely dismissed (Lloyd-Evans et al, 2014).

‘What this effectively means is that, if someone has experience of discrimination and oppression, they can routinely expect to face further discrimination and to be further marginalised by being seen as having less credibility and as a less reliable source of knowledge. This is likely to have the effect of further invalidating people who are already heavily disadvantaged.’ (Beresford, 2016, p.29)

Clinical academic researchers may or may not engage in deliberate efforts to influence this situation, but the reality is that they are supported by the wider social and cultural forces surrounding the production of research (Jones et al, 2014). The peer review process for publication supports this status quo; in an example given by Sweeney (2016), a reviewer states ‘Maybe it is politically correct to include service users’ opinions, but *theory building is not a democratic process.*’ (p.53; my emphasis).

Although we may 'know' that people with mental health problems benefit from a range of psycho-social supports (support with relationships, social activity, benefits, housing etc.), these will be the first to go in a funding crisis as there is no 'evidence' to support them. The evidence for alternatives and for social and relational supports that comes from survivor research (e.g. Faulkner and Layzell, 2000; Kalathil, 2009; Brown and Saini, 2016) can be all too easily overlooked as being qualitative, anecdotal and unrepresentative. The core of treatment will remain the same: medication. This perpetuates the dominance of psychiatry in mental health services and serves the pharmaceutical industry very well despite evidence of poorly executed trials, bias and ethical breaches (Goldacre, 2013).

Jones and Brown (2013) note the parallel effect of the 'clinicalisation' of mental health on service user/survivor knowledge:

“the power to generate knowledge about particular phenomena is allotted ... to academics that have specifically been trained to ‘treat’ individual abnormality or pathology ... mental health research in the US remains almost wholly dominated by clinically trained investigators.” (Jones and Brown, 2013, p.7).

Most significantly, this situation means that little research space is given to theories that challenge or conflict with the biomedical model (Russo, 2012). The power differentials that exist in the clinical setting are perpetuated through research production and continue to influence the knowledge that is given the most status, authority and funding (Jones et al, 2014; Russo, 2012; Beresford, 2010).

Nevertheless, survivor research has continued to carve a space for itself over the last couple of decades, and the work represented in this thesis has made a major contribution to maintaining that space. Whilst some policy changes to the NIHR have eroded the strength of meaningful user involvement in research (Rose, 2014b), there is evidence that survivor research continues (Russo, 2012; Russo and Sweeney, 2016; Staddon, 2013) and that the evolution of 'mad studies' as an academic discipline may act to sustain both its place and its purpose (Sweeney, 2016; Russo and Beresford, 2014).

Whilst service users and survivors doing research remain within the clinical context of mainstream mental health research (user involvement), we remain tethered to the medical

model of understanding mental distress and struggle to release and empower ourselves to find our own epistemologies. We might fly the kite of a social model of understanding (Beresford et al, 2016) but the dilemma remains: the kite is tethered to the medical model. If we want to have a meaningful impact on mental health services and the experience of people coming into contact with them now, today and tomorrow, it is hard to escape from the constraints of mainstream mental health research and the medical model. This is where the potential of the new academic discipline of Mad Studies comes in: in theory, with its multi-disciplinary approach and deliberate foregrounding of survivor knowledges, Mad Studies can release the kite from its tether and let it fly free.

LeFrancois et al (2013) define Mad Studies as 'a project of inquiry, knowledge production and political action devoted to the critique and transcendence of psy-centred ways of thinking, behaving, relating and being' (p.13). It is creating a credible space for the validation of survivor experiences and knowledge, positioned in opposition to biomedical psychiatry and the clinicalisation of mental health experience described by Jones and Brown (2013). Mad Studies allows for the contribution of grassroots activism as well as intellectual endeavour and in this, owes a significant debt to the field of disability studies in transforming - or aiming to transform - the broad category of 'madness' in the way that disability studies has done for 'disability'. In theory at least, Mad Studies could become the new home for survivor research and the survivor researchers of the future. Much depends on our ability to work with marginalised and racialised communities in building a more complete picture of survivor knowledges and experiences (LeFrancois, 2015).

4.4 MY DEVELOPMENT AS A RESEARCHER / REFLECTIONS ON UNDERTAKING THIS THESIS

As this thesis draws to a close, I cannot help but reflect upon the privilege I carry with me in being able to undertake this work. I may have had a number of extended periods of mental distress and had some very poor experiences of mental health services, but I have also had the privilege of being white with a middle class education - not to mention the financial resources to support the process. Never has this privilege been more evident to me than now, towards the end of my career, as I write this thesis. David Webb, writing in *This is Survivor Research* (Sweeney et al, 2009) about how being a survivor researcher has helped him survive, writes:

‘Research - ‘disciplined enquiry’ - is a wonderful and privileged opportunity to pursue the spirit of ruthless enquiry, on which my personal sense of well-being depends... Research helps keep me sane in my madness. Research keeps me alive.’ (Webb, 2009 p170).

Writing about my experiences has helped me to make sense of them and to set them in context, alongside the experiences of my peers and others who live and write with mental distress. Writing has often been central to my survival, as is demonstrated by many of these publications (Paper 10 in particular) but also, for example, the columns written for the magazine *Mental Health Today* (Outside the Box, written bi-monthly from 2008-2015). Giving voice to my experiences in writing has enabled me to take some level of control over them and to gain from sharing them with others.

This has been a long journey. When I first started out as a researcher in the 1980s, I believed that there were facts to be revealed, and now as I write this thesis, I am more than ever aware of the different perspectives and different truths that can be revealed in different ways. I feel that I am now more prepared to adopt less traditional methods, and would now explore narrative and autoethnography as approaches. Given the opportunity to do 'Strategies for Living' again now, I would do fewer narrative interviews with more depth and a different approach to reflexivity, giving participants the opportunity to reflect and comment upon the findings, and to have more control over the final research narrative.

My identity and my story has changed and will continue to change as I continue. In the late 1990s, when I first came to identify myself as a service user, I could not have imagined writing this thesis. However, I do believe that those of us who engage in this kind of academic endeavour have a responsibility to make their thinking accessible to our communities of service users and survivors. I plan to find ways of doing this both through writing and through presenting using contacts at City, University of London and the National Survivor User Network (amongst others).

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GLOSSARY OF KEY TERMS

POWER

Power is a central concept for this thesis. Power operates within mental health services and beyond, to the disempowerment of people diagnosed as mentally ill, but it also operates more broadly within structures that enable the production of knowledge, to the detriment of marginalised communities that include people deemed mad. However, as many theorists including Foucault (1977) have argued, power is everywhere and is not necessarily a negative force, but is operating throughout our social worlds between us all as social beings. Foucault has been influential in highlighting the ways in which power operates to establish social norms in society, which cause us to discipline ourselves without any apparent coercion from others (Gaventa, 2003). According to this framework, an individual does not possess power but is able to exercise power within the context of a range of reinforcing or challenging social and structural relations. In other words, there is a range of social, institutional and research settings operating to '*collectively* shape discourse concerning legitimate or illegitimate knowledge and research practice' (Jones et al, 2014).

Foucault used the term 'power/knowledge' to signify that power is constituted through accepted forms of knowledge, scientific understanding and 'truth' (Foucault, 1977). Where there is a fundamental power imbalance, as there is between mental health researchers and service users/survivors, the knowledge is controlled by those with the power, resulting in the dominant biomedical paradigm in the 'mental illness' discourse.

IDENTITY

In a similar way, identity is socially negotiated between an individual and society and can be mediated by power. Identity can be conceived of as a combination of the individual self (components of how I see myself in relation to others) along with a totality of attributes including beliefs about one's characteristics including life history, and the personal characteristics and behaviours displayed to or shared with others. Importantly, this includes belonging to or membership of particular social groups. A shared or collective identity can give a positive sense of belonging and self-esteem through membership of a group, but can also have negative social effects through disadvantage and discrimination of that group (the

mediation of power). Whilst some aspects of identity may be fixed over time, many others are changeable whether explicitly (e.g. gender transition) or implicitly and according to social context. Part of this is understood through the 'othering' of minority and marginalised groups, in that membership of a marginalised group will invite an identity label that membership of the mainstream majority does not.

Crenshaw (1989) coined the term intersectionality to convey the idea that all aspects of an individual's identity interact with each other and affect their/our identity and position in society. Intersectionality helps us to understand some of the failings of identity politics as it highlights that individual aspects of identity cannot be observed separately. Identity politics refers to political positions based on the interests and perspectives of individual social groups with which people identify; it tends to occlude the differences between people within a single group, differences that may be overlooked in single identity actions. This is of particular value to us in the mental health service user/survivor movement as we need to understand the 'inconvenient complications' of our differences and diversity (Jones and Kelly, 2015). There is no single service user/survivor identity or perspective, and many initiatives to 'involve' service users in an activity fall into this trap. As such, intersectionality is not simply a view of personal identity, but provides us with a means to understand how multiple systems of oppression interrelate with each other.

EXPERIENTIAL KNOWLEDGE

Experiential knowledge is knowledge gained through experience, as opposed to professional or textbook knowledge. As outlined in this thesis, Borkman (1976; 1990) describes experiential knowledge as based on having undergone specific and affecting life experiences, arguing that it is '...specialized knowledge, grounded in an individual's lived experience' (Borkman, 1990, p.3). Borkman goes on to describe 'experiential authority' as the result of a process of legitimising or giving credibility to the knowledge gained through personal experience. This process may take place in research but also within the self-help and peer support spaces where service users come together and share their experiences, develop strategies and support each other.

Experience as an essential category has been challenged by Scott (1991) and more recently by Voronka (2016). It is problematic to assume one over-arching category of experience and

therefore of experiential knowledge, because this is at risk of effacing the differences between us. It may be more helpful and more accurate to think in terms of 'experiential knowledges' to reflect the differences between us as service users and survivors (see Identity above). More particularly, this highlights the problem of being 'people with lived experience' within an involvement activity, where the category is assumed as essential and raises questions about representation. Ultimately, it is important to question our roles when we embark on such initiatives and find ourselves defined and circumscribed by our experience/identity.

STANDPOINT THEORY

Standpoint theory offers us a way of understanding the world from different, socially situated, positions. Feminist standpoint theorists make three principal claims: that knowledge is socially situated; that marginalised groups are socially situated (at the margins) in ways that make it possible for them to see the world in a different, more complete, way to those who speak from the dominant centre; and that research should begin with the lives of the marginalised. Thus, there is no 'universal knowledge' but rather different knowledges or truths produced from different standpoints. Whilst this opens up standpoint theory to being criticised for being ultimately relativist (Hekman, 1997), there is strength in exploring the relations between power and knowledge and in foregrounding the knowledge that comes from marginalised groups. Harding's (1993) original analysis concerned marginal lives in general and the fact that their experiences and lives have been devalued and ignored as a 'source of objectivity maximizing questions - the answers to which are not necessarily to be found in those experiences or lives but elsewhere in the beliefs and activities of people at the center who make policies and engage in social practices that shape marginal lives' (Harding, 1993, p.54). The concept of 'strong objectivity' suggests that marginalised groups have a more complete knowledge because they have access to the mainstream discourse as well as to their own marginalised knowledge (Harding, 1993).

Once again, we have to ask if there is any validity in conceiving of a collective mental health service user/survivor standpoint or a myriad of standpoints to reflect the 'inconvenient complications' of our intersectional identities. Beresford and Boxall (2013) suggest that mental health service users are united by having been on the receiving end of 'collective

solutions based on perceived or accredited 'mental illness' (p.77). They suggest that knowledges developed from a mental health service user/survivor standpoint should be assessed by 'their challenge of injustice, their creation of cultures of resistance and their transformative potential in the lives of mental health service users'. Nevertheless, it seems vital to retain the plurality of these perspectives, identities and standpoints.

APPENDIX A: LETTERS FROM CO-AUTHORS

1. Rosemary Barber, University of Sheffield (Paper 4)
2. Mike Crawford, Imperial College London (Report 2, Papers 5 and 6)
3. Thurstine Basset, Basset Consultancy (Papers 7 and 8)
4. Sarah Layzell, independent counsellor (Report 1)



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Alison Faulkner

15 March 2016

Dear Alison

Re: Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health*. Volume 13, Number 6, December 2004, pp. 549-559.

I am happy to confirm that Alison Faulkner made a substantial contribution to the writing of the above publication. The paper reflects discussions and exchanges of ideas between the two authors, with important and significant writing from Alison. Both authors approved the final draft.

With best wishes

Rosemary

[redacted]
Honorary Senior Research Fellow
University of Sheffield
Section of Public Health
School of Health and Related Research

18th March 2016

Dear colleague,

Re: Alison Faulkner

I am writing to you regarding the major contribution that Alison Faulkner made on the NIHR funded 'Learning the Lessons' study: <http://www.nets.nihr.ac.uk/projects/hsdr/081404083>

Alison together with Sarah Gibson took a lead in a qualitative component of the project in which experts by experience examined the views of service users about specialist community services for people with personality disorder. Alison provided training and supporting the interviewers and then took a joint lead with Sarah Gibson in the analysis and reporting of data. This work formed a central component of the main project report and two other papers (one which Alison wrote and the other which she made a substantial contribution to).

1) Crawford, M et al* (2007) Learning the lessons: A multi-method evaluation of dedicated community- based services for people with personality disorder. National Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health. *18 authors listed.

2) Price K, Gillespie S, Rutter D, Dhillon K, Gibson S, Faulkner A, Weaver T, Crawford MJ. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health* 18,467–475.

3) Faulkner, A., Gillespie, S., Imlack, S., Dhillon, K. and Crawford, M. (2008) Learning the Lessons Together. *Mental Health Today*, February, 24-26.

Yours sincerely

[REDACTED]

[REDACTED]

Basset Consultancy Limited

Flat 2, Rutland House, 111 Marine Parade, Brighton BN2 1AT

T:

E:

14.03.2016

To whom it may concern

Re: Alison Faulkner's PhD by Prior Publication

The two papers below were jointly written by Alison and me:

- Faulkner, A. & Basset, T. (2012) A helping hand: taking peer support into the 21st century, *Mental Health and Social Inclusion*, Vol. 16 (1), pp.41 – 47.
- Faulkner, A. and Basset, T. (2012) A long and honourable history. *The Journal of Mental Health Training, Education and Practice*, Vol. 7: 2, pp.53 – 59.

Both papers originated from work that Alison and I did for Together when that organisation was seeking to put peer support in mental health at the top of their agenda for development.

This work was published by Together in 2010 and we subsequently wrote both papers to further develop and promote the work.

Alison was the lead writer for both papers, which drew on research done for Together where Alison also took the lead and I assisted her in her role, when needed.

Yours Sincerely

[Redacted Signature]

Director

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED] / [REDACTED]
[REDACTED]
[REDACTED]

28th March 2016

To whom it may concern,

Re: Strategies for Living; Faulkner, A and Layzell, S; Mental Health Foundation, 2000.

I confirm that I worked with Alison Faulkner on the analysis and report writing for this report.

Alison managed the research design and process and led on the analysis and report writing. My role was to analyse sections of the research and write first drafts of the chapters describing the research findings.

I hope this information is helpful.

Yours sincerely,

[REDACTED]

[REDACTED]

KNOWING OUR OWN MINDS: THE ROLE AND VALUE OF EXPERIENTIAL KNOWLEDGE IN MENTAL HEALTH RESEARCH

THESIS SUBMITTED FOR PHD BY PRIOR PUBLICATION
VOLUME TWO: PUBLISHED PAPERS SUBMITTED FOR THIS PHD

ALISON FAULKNER

MARCH 2017

CENTRE FOR MENTAL HEALTH RESEARCH, SCHOOL OF HEALTH SCIENCES
CITY, UNIVERSITY OF LONDON

LIST OF THE PUBLICATIONS SUBMITTED FOR THIS THESIS

REPORTS

1. Faulkner, A. and Layzell, S. (2000) *Strategies for Living: a report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.
2. Crawford, M. et al* (2007) *Learning the lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder*. National Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health. *18 authors listed.
3. Faulkner, A. (2010) *Changing Our Worlds: Examples of user-controlled research in action*. Eastleigh: INVOLVE.

PAPERS

4. Telford, R. and Faulkner, A. (2004) Learning about service user involvement in mental health research. *Journal of Mental Health*. Volume 13, Number 6, December 2004 , pp. 549-559(11)
5. Price K, Gillespie S, Rutter D, Dhillon K, Gibson S, Faulkner A, Weaver T, Crawford MJ. (2009) Dedicated personality disorder services: A qualitative analysis of service structure and treatment process. *Journal of Mental Health* 18,467–475
6. Faulkner, A., Gillespie, S., Imlack, S., Dhillon, K. and Crawford, M. (2008) Learning the Lessons Together. *Mental Health Today*, February,24-26.
7. Faulkner, A. & Basset, T. (2012) A helping hand: taking peer support into the 21st century, *Mental Health and Social Inclusion*, Vol. 16 (1), pp.41 –47.
8. Faulkner, A. and Basset, T. (2012) A long and honourable history. *The Journal of Mental Health Training, Education and Practice*, Vol. 7: 2, pp.53 – 59.
9. Faulkner, A. (2012) The Right to Take Risks: service users' views of risk in adult social care. *The Journal of Adult Protection* Vol. 14 (6), pp.287 – 296. [Emerald Literati Highly Commended paper]
10. Faulkner, A. (2005) Institutional Conflict: the state of play in adult acute psychiatric wards. *The Journal of Adult Protection* 7 (4), 6-12.



STRATEGIES

for living

A report of user-led research into people's strategies
for living with mental distress

This report was written by Alison Faulkner and Sarah Layzell, with contributions from Mina Sassoon, Helen Blackwell and Elsie Lyons, Colin King and Jan Wallcraft. The research was carried out by Jan Wallcraft and Alison Faulkner, with the interviewers on the project who were: Helen Blackwell, Elsie Lyons, Kika Everington, Colin King and Mina Sassoon.

Funded by the National Lottery Charities Board

ACKNOWLEDGEMENTS

We could not have written this report without the many people who agreed to be interviewed; many thanks to all of them for taking the time to share with us their lives, their distress and their 'strategies for living'.

An enormous 'thank you' is due to the five interviewers on the project: Helen Blackwell, Elsie Lyons, Kika Everington, Colin King and Mina Sassoon, for their hard work and dedication to the project.

The continued support of our Advisory Committee has been invaluable in grounding the project in the real issues, and encouraging us with warmth and enthusiasm.

A big thank you is due to Julia Blazdell, Project Assistant, for transcribing many of the interviews – particularly those that were more difficult to hear or understand – and for coding so many of them onto the computer package 'NUDIST', enabling us to begin the analysis with confidence.

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And grateful thanks to those of our colleagues who have provided friendship and personal support throughout the project, as well as comments on early drafts: in particular, Vicky Nicholls, Strategies for Living Research Support Worker, and Lisa Bird, Head of Research and Support Unit.

The Mental Health Foundation would like to acknowledge the support of the National Lottery Charities Board.

Crawford, M. et al* (2007) *Learning the lessons: A multi-method evaluation of dedicated community-based services for people with personality disorder*. National Coordinating Centre for NHS Service Delivery and Organisation R&D, Department of Health.

*18 authors listed.

2.5 User-led qualitative evaluation

This service-user-led module of the study employed qualitative research methods to evaluate the pilot services from the perspective of their current and past service users and carers. The aims of this component of the study were to explore individuals' experiences of the services with a view to identifying factors which are believed to influence perceptions of service quality and outcomes for service users, and those which affect eligible service users' decisions to engage, or end contact, with services.

2.5.1 Recruitment, training and supervision of service user researchers

A team of 11 Service User Research interviewers was recruited via service user research groups and networks across England during the autumn of 2005. In January 2006, they undertook four days of intensive training delivered by a Mental Health Foundation-based research team. The training provided information about the background to the project, as well as detailed information on qualitative research methods, including managing bias, recruitment and sampling strategies, interviewing skills, use of the interview schedule, ethical issues and plans for supporting and supervising user researchers, in order to ensure consistency of approach across the different pilot sites. Telephone and face-to-face peer support and research supervision were provided throughout the period of data collection by senior members of the Mental Health Foundation research team. Services also ensured that a familiar member of staff was available to provide support and debriefing for service user / carer participants at the time of or directly after the interview in case they felt the need for support.

2.5.2 Sampling and recruitment strategies

A purposive sampling strategy was employed in order to achieve the aims set out above.

The primary sampling frame sought seven to ten current service users and up to three carers and past service users at each site for individual interviews, plus a further six current service users for at least one focus group interview where this was appropriate to the model of service provision at that site. Within these categories a secondary list of sampling criteria was employed to seek a mix of gender, ages, component of service used and length of contact with the service which was broadly conversant with the mix of service users in contact with each service. Service users who were currently in the process of engaging with the site or ceasing contact with the site and for whom taking part in the research might disrupt their formation or maintenance therapeutic relationships, and service users for whom interview participation might be considered potentially distressing at that point by the staff responsible for their care and support were not asked to participate in the study.

In order to assist with determining the application of this sampling and

Changing Our Worlds: examples of user-controlled research in action

October 2010

About this report

This report was commissioned by INVOLVE and written by Alison Faulkner.

The report has been written for a broad audience, but with the expectation that readers will have some understanding of research.

Information about INVOLVE

INVOLVE is a national advisory group which supports greater public involvement in NHS, public health and social care research. We are funded by the National Institute for Health Research (NIHR).

For further information on INVOLVE please visit our website **www.invo.org.uk**

Information about the author

Alison Faulkner has personal experience as a user of mental health services and a background in research and training. She has experience of leading and supporting research from a service user/survivor perspective and of enabling and supporting service users to become involved in research.

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“

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

Margaret Mead

”

Preface

This has been an enormously enjoyable and inspiring project to work on; the opportunity to meet such a diverse range of projects and people has been amazing. Almost all of them caused me to reflect on my own identity in relation to the identities of the people I met: issues of ‘self’ and ‘other’ recurred in different ways. The process has revived my interest in the politics of research production and the issues of power and empowerment. Whilst I hope that I have treated all of the seven projects fairly and equally, they inevitably raised different issues and feelings for me associated with the powerful themes they addressed.

With my own background in mental health research and as a service user/survivor, the first project I visited, Vision Sense, raised both familiar and unfamiliar issues. Following that visit, I began reading Paddy Ladd’s (2003) ‘Understanding Deaf Culture: In Search of Deafhood’ and reflected on issues of community and culture inspired by learning about Deaf culture. With the Rainbow Ripples group, I felt the greatest sense of a shared identity and empathy. In reading the DITO (Disability, Information, Training, Opportunity) report I was deeply moved and shocked by the experiences of hate crime many disabled people experience in everyday life and wrote my next column for Mental Health Today (Faulkner, 2010) on this subject. In my meeting with Michael Shamash of DITO, we reflected on issues of ‘self’ and ‘other’ and some of the ways in which these attitudes may form in the society around us.

The Thyroid UK project and meetings took me into unfamiliar territory, which made it particularly important to listen well and to get it right when writing it up. Similarly, I have rarely worked with people with learning difficulties; Sarah, Claire and Philip whom I met at Connect in the North made me feel very welcome and shared very openly with me their hopes and experiences. The young people from Get the Life You Want (GLUW) and Have Your Say were truly inspiring and, once again, made me think about some new and unfamiliar issues; for example, the immense and additional loss for children and young people who are separated from their siblings in the care system.

Alison Faulker

July 2010

Acknowledgements

First of all, I would like to thank all of the people who agreed to take part in this project and shared their experiences, often with considerable passion and enthusiasm. Through them, thanks go to the many participants in each of the seven projects, people who I did not get to speak to but whose lives and experiences are represented here.

Particular thanks go to Vida Field for her help and support throughout the project: assisting with interviews, transcribing tapes, and commenting on drafts.

Thanks to Michael Turner, Mark Pettigrew and Patsy Staddon who each reviewed an earlier draft of the report and provided helpful insights and comments.

The Advisory Group of Mary Nettle, Rosemary Barber and Lucy Simons were a joy to work with and gave wise and supportive advice throughout. And I would like to thank INVOLVE, and in particular the Empowerment Working Group, for commissioning this piece of work.

Alison Faulkner

July 2010

Report summary

The aim of this project was to increase understanding and awareness of the role and value of user-controlled research through exploring in-depth seven examples of research where service users or disabled people controlled the research process (see the table on page 13 and the individual examples for more information about the projects).

User-controlled research

There are different ways of referring to and defining research conducted or controlled by service users, and some people use the terms ‘user-led’ and ‘user-controlled’ research interchangeably. Turner and Beresford, in their report ‘User-controlled research: its meaning and potential’ published by INVOLVE in 2005, suggest that control by service users is the key defining characteristic of user-controlled research, but that making change happen is commonly identified as its central purpose.

Researchers and service users and other key people were interviewed about their project. Questions covered: the origins of the research, the methods used, the nature and extent of user control over the research, and the dissemination and impact of the research findings.

1. The reasons for doing user-controlled research identified by these seven projects were:

- To make change happen
- To highlight the needs of marginalised groups
- Because ‘No-one else will do it’

All of the projects originated out of a commitment to changing or improving the lives of their community of service users, whether directly or indirectly, locally or nationally. Findings from the projects suggest that user-controlled research often arises from within groups of people frustrated by traditional research that overlooks or excludes them and/or services that do much the same thing. Frustrated by the failure of mainstream research to capture their needs or research the things they thought important, they found ways of doing so themselves.



Somebody needed to tell the story of our lives as LGB [lesbian, gay and bisexual] disabled people.

Rainbow Ripples



Through raising awareness of the experiences and needs arising out of their lived experience, groups like lesbian, gay and bisexual disabled people, young people in care, disabled people and Deaf people with mental health needs placed themselves on the map of human experience and were able to exert some influence on local and/or national service or policy development.

2. The projects demonstrated a range of different ways of doing user-controlled research. These included different:

- Research approaches
- Organisational bases
- Levels of control
- Sources of funding

Three projects employed or contracted service user researchers or disabled people to undertake the research; three adopted a 'capacity-building' approach in which service users were trained and supported to participate as researchers; and one undertook a clinical study coordinated by the group. A variety of methods included focused events in which people shared their experiences, and the more conventional use of questionnaires, interviews, and focus groups. Common to all of the projects was a shared identity between the researcher(s) and the research participants.

The extent of control by service users varied across the seven projects. Absolute control depended on service users having independent funding (and having control of that funding) as well as a user-controlled organisational base. Having control over the research was seen as vital by all of them. Many of the people interviewed spoke passionately about the significance of having control, both to themselves and to their organisation and their wider community of service users.



It just wouldn't have happened if we hadn't had that level of control.

Rainbow Ripples



3. The benefits of user-controlled research were identified as:

- Making change happen
- Access and trust
- Improved research quality
- Empowerment
- Credibility

Amongst these seven case studies are some powerful examples of user-controlled research making a difference. As stated earlier, all of the projects were committed to making change for the benefit of their community of service users. What is perhaps surprising is the degree to which they achieved this, given their scale and the size of their budgets.

A shared identity between the researcher and participants meant that trust could be established, particularly when conducting face-to-face interviews and focus groups, leading to improved access to participants and to open and honest accounts about the issue under investigation.

“

It's people who know asking people who know.

Connect Works

”

The value of a shared identity was also demonstrated when it came to designing the research, deciding upon the questions and analysing and interpreting the findings. The 'insider knowledge' ensured that the research would address the right questions, and be interpreted by people with an understanding of the nature of that lived experience.

For some projects, the increased accessibility that this shared identity brought with it was central to the success of the research. For example: a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group.

Empowerment has been identified as a key principle of user-controlled research. These projects help us to understand empowerment and how user-controlled research can bring about empowerment for the service users involved. It was most often mentioned in connection with the two projects that involved supporting service users without previous research experience: the young people's projects and Connect Works. The young people talked of the opportunity the research had given for them to learn new skills and gain confidence. Empowerment reached out beyond the research and into people's lives.

“

People take us more seriously. That's what empowerment is. Empowerment: you know you can do it.

Young Researcher Network

”

4. The challenges of user-controlled research encountered by these projects included:

- Resources
- Discrimination
- Dilemmas surrounding identity and power
- Distress

In nearly all of the projects, individuals and organisations had contributed additional resources over and above the funding they had received. Some contributed their time and skills for free because of their commitment to the research. Others subsidised the available funds, whether in terms of actual money or staff time or both, in order to ensure their success.

Many of these projects represented people facing multiple discrimination. For at least two researchers, this became a very real part of the research process; one experienced abuse as he left one of the interviews and one researcher received abusive emails in response to publicity about the research.

Having control over the research did not necessarily mean that issues of control and power were predetermined or unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. It could lead to people asking more of the researcher than they could perhaps offer, or to some discomfort on the part of the researcher about their role and the power they had adopted in relation to their interviewees. In addition, this shared identity could at times lead to distress on the part of researchers who shared difficult experiences.

All of these challenges highlight the importance of building in good supervision and support for service user researchers and ensuring that lone workers in particular have adequate opportunities for de-briefing and supervision.

5. The impact of user-controlled research demonstrated by these projects can be seen in relation to their:

- Impact on service users
- Impact on the research
- Impact on services
- Impact on policy

Nearly all of these projects had achieved what they set out to do, in making change happen. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development.

Service user/researchers involved in these projects talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research. Many of the projects resulted in tangible outputs which aimed to extend their impact to their wider community of service users. Examples of these include: training packs, information packs and dedicated website, a training programme, DVDs and an improved pathway through mental health services.

Several projects were able to make use of their relationships with powerful allies to impact upon change. The Vision Sense project worked closely with a Deaf commissioner, who was able to understand the issues and politics surrounding the culture of Deaf people; Thyroid UK had a medical ally to assist them with their research as well as a wealth of expertise amongst their members; the National Youth Agency's Young Researcher Network acted as an ally in enabling the successful dissemination of the two YRN projects.

Some of the projects also achieved an impact on national policy, whether by virtue of their efforts at disseminating the findings, or through support from their funding body. Recommendations from the Rainbow Ripples report entered the Commission for Social Care Inspection inspection guidelines. Connect Works, through dissemination via the Skills for Care website may have had an impact on personalisation policy in relation to people with learning difficulties. The young people's projects were enabled to disseminate their findings at a national level through support from the National Youth Agency's Young Researcher Network, including taking part in a House of Lords' debate.

Introduction and background

This is the report of a project commissioned by INVOLVE with the aim of increasing understanding and awareness of user-controlled research. Through exploring a small number of projects in detail, the aim was to reach a better understanding of the role and value of user-controlled research. This study was designed to complement a previous mapping exercise, also commissioned by INVOLVE, which identified 45 examples of user-controlled research across the health and social care spectrum. These projects formed the pool from which these seven projects were selected for more detailed exploration. Further details including published reports and links to the project websites can be found on the INVOLVE research project database on the INVOLVE website (www.invo.org.uk).

There are different ways of referring to and defining research conducted or controlled by service users, as outlined in Michael Turner and Peter Beresford's report: 'User-controlled Research: its meaning and potential' published by INVOLVE in 2005. Some people use the terms 'user-led' and 'user-controlled' research interchangeably. However, others see a clear distinction between the two, where 'user-led' research is only partially controlled or directed by service users and/or is supported by a non-user-controlled organisation. Turner and Beresford suggest that control by service users is the key defining characteristic of user-controlled research, but that making change is commonly identified as its central purpose.

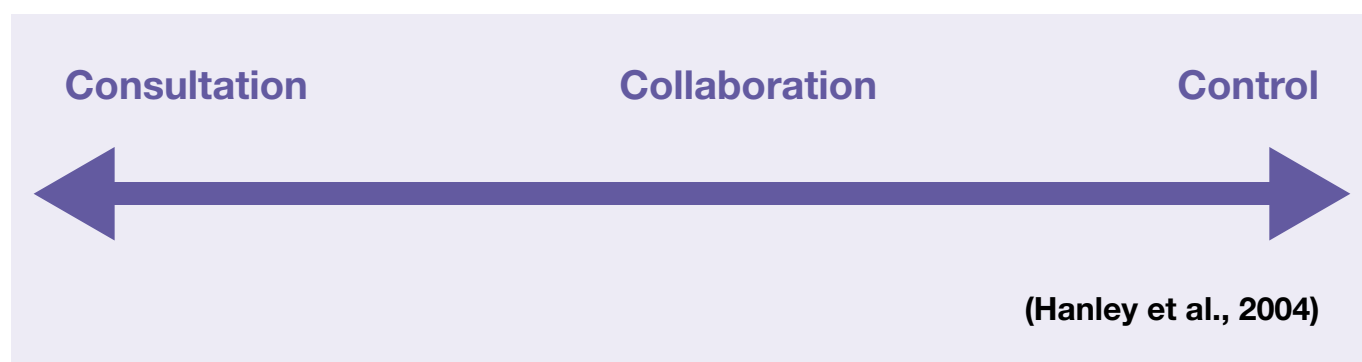
They further identify the aims in terms of:

- Empowerment – both through the process and the purpose of the research
- Being part of broader social and political change
- More equal relations of research production
- Being based on social models of understanding and interpretation.

The value of finding out more about user-controlled research lies partly in its ability to tell us more about one end of the proposed continuum of involvement (see below).

Most public involvement in research is concerned with the large and varied area in the middle of this continuum, with the research itself largely controlled by professional academic researchers. There are many examples of good practice in collaborative research (see, for example, Langston et al., 2005; Faulkner et al., 2008) and growing evidence of its impact (Staley, 2009). However, for many people coming from a service user perspective this approach is seen to 'embody inequalities of power which work to the disadvantage of service users' (Turner and Beresford, 2005; p. iv).

This report, then, turns our gaze towards the different situations in which service users (patients, members of the public) have seen the need to do their (our) own research rather than becoming involved in research directed by others. The focus here is on the value it has to those undertaking it and the difference it makes to the research, the research impact and the research experience when the agenda is clearly held and directed by service users.



User-controlled research has its origins in service users' dissatisfaction with traditional research (see Turner and Beresford, 2005), but also often in people's frustration with the services that fail to listen to them, as this report will demonstrate. There are a number of research traditions that have influenced or hold features in common with 'user-controlled' research. Perhaps the main one of these is emancipatory disability research which aims to empower or liberate service users through the research process. Research can emancipate disabled people/service users through challenging traditional research methods, adopting an inclusive and participatory approach to research, and through describing people's individual or collective experience in their own terms.

Survivor research (research by mental health service users/survivors) shares a common pathway with emancipatory research, in that it is controlled by mental health service users and has the aim of empowerment at its heart (Beresford and Wallcraft, 1997; Faulkner, 2004). Feminist research also began by taking a 'standpoint' approach, aiming to overturn the traditional roles of the researcher and the researched through sharing identity and understandings with the research participants. Key to these approaches is a transparency about the identity, perspective and approach undertaken by the researcher. This is followed through in user-controlled research in the range of ways in which service users undertake and control research that amplifies certain aspects of their own lives and experience.

One of the disappointments for this study was that no projects from black and minority ethnic (BME) communities were identified at the mapping stage; the author communicated with Jayasree Kalathil (a Black survivor researcher involved in the mapping project) about this issue. Kalathil suggested that these are concepts and modes of working that have developed within a survivor movement in which BME service users had very little role to play.

“

Even today there are very few BME user researchers around, very little money to train/sustain BME user researchers. Very little opportunities for BME user researchers to find work, especially in “general” projects that are not in some way ghettoised...I just feel there might be other definitions of how people see ‘control’.

Kalathil, personal communication

”

The issue of control is discussed in later in the report (see the section on the role and value of user-controlled research) and allows that there were different levels and interpretations of control across these seven projects. Nevertheless, we must remain mindful of the fact that few Black or minority ethnic communities are directly represented in these projects. The one exception to this is the Shaping Our Lives project, Relationship Matters; their project steering group consisted of 12 members, six of whom were from Black and minority ethnic communities. Across the five groups involved in the project, participants included Black and minority ethnic service users and Welsh speakers, amongst a diverse range of service users and disabled people.

The aim of this study, then, was to explore a sample of between six and eight examples of user-controlled research, with a view to examine in detail the role and value of user-controlled research.

Methods

1. Selection of the seven projects

Forty-five projects had been identified in the initial mapping project. As projects had defined themselves as user-controlled research, it was necessary to assess their suitability for inclusion for the case studies. For example, some projects may have a high level of user involvement but were not actually controlled by service users. Therefore, a structured process was followed to select projects; this was carried out by members of the Project Advisory Group and Karen Postle, then a member of the INVOLVE Coordinating Centre.

Each project was reviewed by two people, using the information submitted to the mapping project. The reviews were carried out independently and then collated. With the information available, each project was checked against four criteria:

1. The projects are/were **user-controlled** – a definition derived from the Turner and Beresford report (2005) was used: Research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. Service users will run the research advisory or steering group and may also decide to carry out the research.
2. The projects are/were **research** – a broad definition of research was used and all projects that set out to answer defined questions and followed a systematic process to collect and analyse information were included. If projects appeared to be service development work or consultations they were excluded.

3. The topic was relevant to health, public health and social care research.
4. The project was ongoing or completed within the past two years.

Where there was agreement between the two reviewers that all four criteria were met, the projects were added to the list for possible selection for the case studies. This led to a short-list of 19 projects.

The short-listed projects were organised into seven themes: learning difficulties; mental health; young people; general health; disabled people; lesbian, gay, bisexual and transgendered people; and general user involvement. Across these themes the projects were then listed in rank order to achieve greatest diversity across the range of other factors including funding source, aspects of user-control and any distinctive features of the projects. The project at the top of the ranked list for each theme was approached successfully.

The final list of projects included is set out in the table on page 13.

	Project title	Date of completion	Organisation	Theme
1	Deaf People's Mental Health Pathways	2008	Vision Sense	Mental health
2	Comparison of urine and blood tests for thyroid function	Ongoing	Thyroid UK	General health
3	Connect Works (what people with learning difficulties want from personal assistants)	2008/9	Connect in the North	Learning difficulties
4	Disability Hate Crime	2007	DITO (Disability Information Training Opportunity)	Disability
5	The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual disabled people in Leeds)	2006	Rainbow Ripples	Lesbian, Gay and Bisexual
6	1. Get the life you want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	2008/9	Supported by the National Youth Agency Young Researcher Network	Young people
7	Relationship Matters	2008/9	Shaping Our Lives	General user involvement

In practice, the project identity themes overlapped, with disability being a theme to (arguably) five of the projects.

For example 5 the completion date of the project was reported as 2008 in the information submitted to the initial mapping project. Once contact had been made with the user researchers and the actual completion date confirmed we felt committed to include the project in this report.

2. Questions

The second stage was to formulate a topic guide or set of questions to be asked about each project. A preliminary list of questions was amended following discussion with the advisory group and with each project as interviews progressed. A copy of the final list is attached in Appendix A. A secondary list was prepared for the commissioner approached for the Vision Sense project. Interviews did not necessarily follow this list rigidly however; they were regarded as semi-structured conversations and often diverged to discuss interesting tangential issues.

3. Interviewing and data collection

Site visits and group or individual interviews were undertaken with six of the projects; telephone interviews alone took place with project 7. Supplementary interviews or emails were undertaken where key informants were unable to be present at a site visit. For example, the project undertaken by Vision Sense was commissioned by the PCT so a telephone interview was set up with the relevant commissioner. Most of the interviews were recorded and transcribed for subsequent analysis and accurate quotation.

It was not possible to contact all of the people involved in the production of all of these projects. Some people did not respond to approaches made; others were no longer involved with or employed by the original organisation and proved impossible to find. There is always the possibility that those people who did not respond may have held different views about the projects than those who did respond.

4. Other sources of information

Copies of reports were another important source of information. Where possible, all of the project reports have been referenced for access by the readers of this report. Another important source of information was the internet. In some cases, it was possible to trace where a research project had been referenced on the web for use by third parties (e.g. the Department of Health in the case of the Rainbow Ripples report; the London Borough of Tower Hamlets for DITO's (Disability Information Training Opportunity) Disability Hate Crime research, and so on).

5. Feedback to projects

The first draft of each written example was sent back to the project participants to check for accuracy; amendments were made accordingly. They have also had the opportunity to review and comment on the full report prior to publication.

6. Structure of the Report

The seven examples are presented separately in the following sections. The presentation of the examples varies a little in line with the individuality of the projects; hence not all of the sub-headings used are consistent. Quotations have only been attributed to the speaker where a number of people with different roles were interviewed (e.g. researcher, commissioner, disabled person).

After the seven examples, a commentary on the themes and issues arising from the examples is presented in the section The role and value of user-controlled research.

The final part of the report summarises the main conclusions from this project.

Example 1:

Deaf people's mental health pathways – Vision Sense

Summary

This project explored Deaf people's experiences of mental health services with a view to improving their pathways through services for the future. It was carried out by Vision Sense, an independent, user-led, not-for-profit organisation, based in the North East of England (www.visionsense.co.uk), for the North East Commissioning Team for Mental Health and Learning Disabilities which is hosted by County Durham NHS PCT. The report was delivered in 2008. Technically it was a service evaluation; it did not require approval from a research ethics committee.

In this report, the term 'Deaf' is used for those who are born Deaf, mainly communicate through sign language and see themselves as part of a Deaf cultural community and 'deaf' for people who have acquired deafness and mainly use oral means of communication. The term D/deaf includes both communities.

Interviews were carried out with Susie Balderston of Vision Sense, researcher Verity Joyce, and Matthew James, commissioner.

Origins of the Project

The project was initiated by the Commissioners, partly as a result of the Department of Health report 'Towards Equity and Access' on mental health and deafness (Department of Health, 2005) and partly in the wake of two serious incidents involving Deaf people with mental health needs. The commissioner was asked to improve the mental health pathways for Deaf people in the North East; to move away from a pathway based on one specialist mental health nurse for all Deaf people with mental health needs in the region, and to improve outcomes for people whose main care was provided out of area. The Towards Equity and Access report meant that money was available to commission services that would improve the mental health pathways of D/deaf people in the region. The Commissioner was himself Deaf, so he had an understanding of Deaf culture and the importance of a user-led approach to the work.

The Project

The Commissioners designed the brief for the work and commissioned Vision Sense to carry it out. Vision Sense employed two Deaf researchers to find out from service users and carers their views and experiences of mental health services being used by Deaf people. The project steering group included representatives from the local NHS Trusts, the commissioners, local authority, Vision Sense, Northumbria University, and the Deaf researchers.

The project entailed a literature review, interviews with Deaf mental health service users and recommendations for the design of a mental health pathway. Interviews were undertaken with eight people who self-selected to be involved in the project, and two discussion groups reached 12 more. Participants were identified through a snowballing method aided by the Deaf researcher's contact. The researchers took written notes of the interviews; ideally they would have been video-recorded but the time and costs for this including culturally competent translation and transcription would have been prohibitive. Nevertheless, being Deaf herself, the researcher was able to translate their words back into the way in which they communicated with her initially, remembering and using their expressions and mannerisms.

Control

Service user control of this project was not absolute, in that it originated with the commissioner and needed to meet the brief given. In his opinion, it was essential for the project to take place in what he considered to be a 'neutral' organisation and to be user-led, in order that it would fulfil the requirements of the commissioning cycle.



Commissioning now is about putting the patient at the centre. If you don't do that, then what you try to do in making a difference won't be widely accepted.

Matthew James



The research element was controlled by service users in the form of Vision Sense and the Deaf researchers. It was undertaken within Vision Sense's ethos of 'a strong commitment to the clarity and integrity of the user-led process and outcomes of equality and human rights in its purpose to create evidence, learning and improvement for all our futures.' Vision Sense uses an In Control grid, based on Arnstein's ladder of participation (Arnstein, 1969), to help them decide on taking on projects; if they do not have sufficient control, they will not take it on. This project was unusual for them in having such a direct link to implementation.

Things that helped the project

- A relationship of mutual respect and understanding between Vision Sense and the commissioners created the space for a user-controlled approach to the project.
- The commissioners' commitment to implementing the findings ensured that the project made a real difference to mental health services for D/deaf people.
- Competent Deaf researchers available to carry out the research ensured that the project could be grounded within the culture with integrity and full accessibility for Deaf mental health service users.

Things that made the project difficult

- A challenge for the Deaf researcher concerned the boundaries of her role and responsibilities. In the course of interviewing people who were vulnerable and often unaware of their rights, she found herself challenged ethically, both to provide information and, occasionally, to intervene to find help for someone who was at risk.
- Vision Sense described lengthy negotiations with the commissioners about content and language in the final report, which was resolved by agreeing to write two versions: one to inform commissioning decisions and a summary report for distribution to service users.
- Maintaining integrity: Vision Sense was concerned to keep the language of service users in the report and remain true to the concept of Deafhood and the social model of disability. They resisted using people's diagnoses and worked with the University to ensure that the training also reflected these values.
- Power and control: for the researcher, there was a growing awareness of her own power and influence and the development of her skills in contrast to the people she was interviewing. Coupled with this was an awareness of her relative lack of power in relation to the commissioners, mediated by Vision Sense. Maintaining that balance of power and the trust of the Deaf community was both a challenge and perhaps an integral part of being an 'insider researcher'.

“

I would love to be able to explain it on video because I want to empower them. The whole purpose of the research is to release them from their oppression.

Verity Joyce

”

Making a difference

The report was delivered to the commissioners and used to form the basis of service development. There is now a core specialist team in mental health for D/deaf people, training for mainstream staff (based at Northumbria University), and two Healthy Deaf Minds groups. Vision Sense argued for a second Healthy Deaf Minds group in order to cover another geographical region, and also to ensure that the training was based within an understanding of Deaf culture.

Advice for others

(from the Commissioner)

- Commissioners with a duty to fund user-led research or consultancy need to ensure they have adequate funding to do it.
- It helps to have an independent user-led organisation to undertake the work, to avoid the possibility of creating rivalry between different peer groups.

(from Vision Sense and the researchers)

- Extra time to take account of people's access requirements: e.g. three hours either side of every Steering Group meeting, a personal assistant to go through the papers for a meeting, to work out points people wish to make. With more money and time it could have been more user-controlled, more user friendly; more work could have been done on the translation of the questions into British Sign Language – there is a difference in grammar, facial expressions.

“

It showed that in this case Deaf mental health service users can tell commissioners how it can be and design the service themselves and see that service then be commissioned. This was a new experience for us and a fantastic opportunity to see service users driving developments.

Susie Balderston

”

Further information

Deaf People's Mental Health Pathways:
Commissioning Model Report

An Independent, User-Led Perspective
by Susie Balderston at Vision Sense,
May 2008

To obtain a copy of the report, telephone
0845 108 0553, fax **0191 428 3388** or
e-mail **access@visionsense.co.uk**

Example 2:

Comparison of urine and blood tests for thyroid function – Thyroid UK

Summary

This project was carried out by Thyroid UK, a small registered charity run by people with direct experience of thyroid and related problems with the aim of “Providing information and resources to promote effective diagnosis and appropriate treatment for people with thyroid disorders in the UK” (see www.thyroiduk.org.uk). The personal experience of some of their members (people with continuing problems despite blood test results that fall within the normal range) prompted this research. The aim is to examine and compare the accuracy of two different tests (blood and urine) in relation to people's symptoms. It is a clinical trial, comparing the results of these tests from two groups of participants: a patient group (people who meet the set criteria for hypothyroidism) and a control group (people who meet the set criteria for absence of the disease).

Hypothyroidism is the term given to the symptoms caused by insufficient production of thyroid hormones by the thyroid gland which is in the throat. Symptoms that commonly occur include: tiredness, weight gain, constipation, aches, feeling cold, dry skin, lifeless hair, fluid retention, mental slowing, and depression (www.patient.co.uk accessed 3rd August 2010).

Interviews were carried out with the Chair, Lyn Mynott, the Trustees at the Thyroid UK AGM and with Jane Evans, the study co-coordinator.

Origins of the research

The research arose out of personal frustration and curiosity. Several of their members had experienced the symptoms of hypothyroidism for years before their blood tests showed an abnormal result and triggered the treatment that helped them; as one person said ‘you have lost part of your life’. They came to the conclusion that there was sufficient doubt about the blood test commonly used to diagnose and treat thyroid disorders (the TSH test) to warrant investigation. It is known that various factors can interfere with the accuracy of the blood test, but it remains the gold standard of thyroid testing in the UK. The urine test, which is used by some private practitioners and other European countries in place of the blood test, tests for the end products of thyroid activity and hence may provide a more accurate indication of its function. The team hope that their research will raise awareness of these issues and prompt more research, hopefully a larger study. It is still ongoing at the time of writing. Ultimately, their aim is to improve the treatment offered to people with hypothyroidism.

“

[Researchers] are not asking the right questions – are the tests as good as they should be?

”

The research

The team put the idea for the study into the Thyroid UK newsletter. A subcommittee was formed to coordinate the study. One member had worked as a research study coordinator and offered to help with the study. Dr John Lowe (a specialist in fibromyalgia and hypothyroidism based in the United States) will be advising on the research and doing the statistics. Another Board member will do the initial write-up of the study, and the subcommittee will have joint responsibility for finalising it with Dr Lowe's assistance. Thyroid UK obtained approval from the South London and Surrey Borders Research Ethics Committee based at St George's Hospital. The REC insisted that they use the General Health Questionnaire as well as the team's own screening questionnaire, as the latter had not been validated for this purpose. Since no previous questionnaires had been validated for this purpose, they had carefully selected items from other questionnaires. They felt the need to be '110% perfect' in order to achieve credibility.

The research process begins with the study coordinator carrying out an assessment to ensure the volunteers meet the strict criteria laid out in the protocol. This includes the questionnaire, heart rate and basal temperature, plus a short medical history. The questionnaire has a list of 13 symptoms, scored from 0 to 3; for the patient group, the score has to be over 26, for the control group it has to be 6 or under (questionnaire available from Thyroid UK).

Once these criteria are met and the person is allocated to one of the two groups, the study coordinator meets them at a private laboratory in London. The laboratory lets them have access to a room and carries out the tests at cost. At the time of writing, the team has achieved the 25 participants needed for the patient group, but have only recruited seven to the control group due to difficulties encountered with the body temperature criterion (see right).

Control of the research

This project is unusual in that it is a scientific trial under the control of people with direct experience of the condition. Within that context, the team has had control over the entire project with the possible exception of carrying out the laboratory tests themselves. They designed the project with the help of a medical advisor, have their own study coordinator and plan to write it up themselves, again with the assistance of the medical advisor.



We can do the research that we want, as against doing it the way others want it done.



Things that helped the research

- The main facilitator for the research has been the readiness of members and advisors to volunteer their help. The doctor in the United States has clearly been a valuable support and ally; coupled with the skills and abilities of members (a study coordinator, someone to write the first draft of the study, and journal editors) has made the study possible at low cost.
- The laboratory offering tests at cost has contributed to this.

Things that made the research difficult

- There were problems at the ethical approval stage. One doctor wanted to group people according to their blood test results, but Thyroid UK successfully argued that this would have been accepting the accuracy of the test results and therefore would undermine the purpose of the whole study.
- An anonymous person wrote to the ethics committee saying that they should not be allowed to do this research. However, the ethics committee simply forwarded the message to Thyroid UK and did not act on it.
- The main problem in getting the research completed has been a technical one. For people to be recruited to the control group they have to have a normal body temperature as body temperature relates to metabolism which relates to thyroid function. People who are hypothyroid generally have a low body temperature so in order to ensure controls are 'normal' they need to have a normal body temperature. Unfortunately, of 80 controls contacted to date, only seven have what is considered to be a normal temperature. This in itself is strange – and they may want to do some more research on body temperature later. The medical advisor thinks that a lower number of controls will be adequate for the purposes of statistical analysis.
- The project coordinator had to take a long time off when she was not well, which delayed things to some extent.

Making a difference

Thyroid UK plan to submit papers to journals to publish the results; Dr Lowe, their medical advisor, is editor of Thyroid Science and they have another editor amongst their members – of the Journal of Nutritional and Environmental Medicine. They plan to try the British Medical Journal or The Lancet.

They also plan to publicise the results through their newsletter and other organisations' newsletters, and will try sending their findings to other thyroid organisations such as the British Thyroid Foundation. Also, they are hoping to get involved with the James Lind Alliance, an organisation which facilitates the identification of research priorities shared by patients and clinicians, hence its strap line 'Tackling treatment uncertainties together' (see **www.lindalliance.org**). One of the potential challenges to publication in peer-reviewed journals and wider dissemination is that Thyroid UK is challenging the medical establishment through this research. The hope is that the research will be picked up and will lead to a larger study with more robust statistics.

As an organisation, Thyroid UK wants to do more research, and want to use research to change things:

“

We have to prove to them that the way they [NHS & the medical profession] are doing things is missing people and these people are ill and missing years of their lives.

”

Further information

Thyroid UK is a registered charity

www.thyroiduk.org.uk

Tel: **01255 820407**

Example 3:

Connect Works – Connect in the North

Summary

This project was carried out by Connect in the North (www.citn.org.uk), an organisation led by people with learning difficulties. Connect in the North works to improve services and opportunities for people with learning difficulties. The project used research as the basis for developing a training course to train people to become personal assistants for people with learning difficulties. The aim was to enable people with learning difficulties to be able to choose a personal assistant from a list of people who have already been chosen and trained by people with learning difficulties (The Connect Works Team).



I want to be able to choose who I want to look after me, rather than have others controlling me.

Claire Massa,
quoted in **Community Care,**
23 October 2008



For this case study, a group interview was carried out with Sarah Wheatley, who facilitated the project, and Claire Massa and Philip Hawley, people with learning difficulties who helped run the project. Some additional information has been taken from the Connect Works final report (see right).

Origins of the project

The original idea for the project came from a Connect in the North members meeting. Connect in the North believes that people with learning difficulties should have control over their lives. Training people to be personal assistants is one way of doing this. The personalisation agenda, which has become prominent in recent times, meant that the idea could be realised, as it helped them get the funding to carry it out. Personalisation means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives (Social Care Institute for Excellence, 2010). Funding for the research part of the project came from Leeds City Council. Funding for the training came from Skills for Care: New types of worker money. The people involved were: Claire Massa, Jocelyn Richards, Philip Hawley, David Boyes, Bhupesh Limbachia, Alan Hicks, Manjinder Singh and Susan Hanley (who used to work at Connect in the North) with Sarah Wheatley supporting them.

The research

The team formed two groups: one to work on the research and one to work on the training. The group looked at their own lives as a starting point: they came up with a list of what they would want from a personal assistant and put it up on the wall for people to identify what is good and what is bad. In this way they designed the questions to ask of other people.

In the research, they spoke to 89 people, often in groups face to face, some through questionnaires. They would start a group with an icebreaker and then ask people the questions.

They would put up the answers on the wall and ask people to put stickers or ticks against the things that were important to them. The team would gather up the information at the end. Claire put the information on computer. They also sent out questionnaires to involve other members of the family, but this was not very successful.

The training

The research helped the team to design the training for personal assistants: what training do personal assistants need to make them understand what they have to do. It helped to decide what types of people should come on the training and what was in the training. One thing they found was that values (e.g. treating people with respect) were more important than experience. People also thought that being on time and record keeping were important features.

The team ran the Connect Works training twice. They selected people for the course, ran the training and evaluated the trainers on the basis of their coursework. They then evaluated the course and decided that it needed to be longer. Nine people from the training were chosen to be on a list of personal assistants. This is available to anyone with a learning difficulty who uses direct payments or has an individual budget. The plan for the future is to get the course accredited (see below).

Control of the research

Sarah's role was to facilitate the sessions, to give them a focus. She helped Susan and Claire to decide how to run the sessions. She also wrote up the ideas, writing it up in different ways for the group to decide which was best. They described the control of the project as 'equal but in different ways.' Claire or Susan would come up with the ideas and Sarah would fit it together. It was important to them that people with learning difficulties were in control of the project:



It made a big difference. I enjoyed doing every single bit of it.

Claire

I feel that people who are not disabled who organise these groups don't want to know what disabled people need. We would know what people want. Having disabled people doing this is a big thing. It's people who know asking people who know.

Philip

It's people asking the right questions. I also think it was powerful – people were seeing other people with learning difficulties in valued roles.

Sarah



People with learning disabilities selected people for the training course, trained people and evaluated both the trainees and the course itself, with Sarah's support.

Things that helped the research

The team listed many things that helped:

- Friendship was the main big thing – it had to be there to communicate with each other ‘I miss you all.’
- Working together; being patient, tolerant, understanding, thoughtful; having fun!
- No jargon
- Could slow down so people could keep up; we had breaks
- Being organised – the information was counted up and put on computer [Claire did this]

Things that made the research difficult

- There were differences of opinion amongst the group, but they reached agreement: ‘[we] would put opinions together to get your say into one.’
- Claire said she would get upset sometimes: ‘I would give a bit of my past to show what I meant by something, explaining something.’ They all agreed that there was a lot of support within the group which helped if someone got upset.
- Some participants did not turn up for the training course.

Making a difference

- One of the team, David, now works as an associate trainer, after volunteering for Connect Works. It is his first ever paid employment.
- People have employed personal assistants from the course.
- They have a list of trained personal assistants working in the community.
- People have really changed what they were doing and are happy.
- The 4 week course changed to a 10 week one: it is half a day a week for 10 weeks. It has been run twice
- It was a diverse group of people, which was good. Everyone felt able to share their views.

Future plans

Some barriers for the development of the project were identified in the project’s final report. Connect in the North found that there are barriers to trainers with learning difficulties running accredited training. This is because many organisations funding courses leading to qualifications require the trainers to have a qualification. It is difficult for people with learning difficulties to obtain a qualification in training, although Connect in the North is continuing to explore this. The Open College Network will accredit training led by people with learning difficulties but it is expensive for a small organisation.

Connect in the North are also exploring different ways of funding the training course for the future. These include:

- Contributions from people who have an individual budget
- Core funding from the local authority
- Learning and Skills Council in partnership with a local college.

Further information

Connect in the North

0113 270 3233 info@citn.org.uk

The project is reported on the Skills for Care New Types of Worker website and a copy of the report may be found there:

<http://www.newtypesofworker.co.uk/pages/projects/connect-works/useful-documents>

‘Turning the Tables’ Connect in the North helps people with learning disabilities train personal assistant. Louise Hunt, Community Care, 23 October 2008.

Example 4:

Disability hate crime – DITO

Summary

This study was carried out by DITO (Disability Information Training Opportunity), a small training, rights, employment and community resource run by disabled people based in Mile End in the London Borough of Tower Hamlets. It was funded by the London Borough of Tower Hamlets as part of the work of their Race and Hate Crime Inter-Agency Forum. The aim of the study was to determine the nature and extent of disability hate crime in the Borough. It was undertaken by Michael Shamash, at the time employed as a consultant on the project, and Stephen Lee Hodgkins, at the time Co-ordinator of DITO.

This case study is based on an interview with Michael Shamash and on a reading of the final report of the study. The case study was checked with Stephen Lee Hodgkins, the co-researcher on the project.

Origins of the research

The need for the study was identified as a result of the work of the Race and Hate Crime Inter-Agency Forum in Tower Hamlets, of which DITO was a member. It was felt that little was known about the nature or extent of disability hate crime, a feeling borne out by the study which found very little previous research on the subject. Disability hate crime has long been under-researched and under-reported. Despite the 1996 Hate Crime Statistics Act, under which the police have to report disability hate crime as a separate category, very few such crimes are reported, it is thought largely due to fears of reprisals. This background, together with what Shamash describes as the 'delicate social fabric' of Tower Hamlets, in which the incidence of hate crime is amongst the highest

in London, led to the Borough's interest in commissioning this research. In some ways, it was a case of synchronicity: disability hate crime became a priority through local and national publicity and hence created the conditions for the study to take place.

The research

The research consisted of four stages: a literature review, a small discussion group with disabled people to identify issues, a questionnaire distributed to disabled people, and interviews with key people in the Borough's network of criminal justice, social welfare and voluntary organisations to determine their activities in this area. The discussion group involved five participants, and the questionnaire reached 45 disabled people. The project was funded by the local authority to the tune of £5,000 and hence carried out 'on a shoestring.'

The research revealed high levels of unreported hate crime, much of it psychological (i.e. bullying, harassment, name calling) and much of it occurring on the streets in public places. Incidents were rarely reported, either due to fear of reprisals or because the victim did not think it worthwhile reporting something that would not be acted upon. Recommendations included the need for widespread publicity and profiling, education and training, the need for borough-wide coordination, the wider use of third party reporting sites and support for disabled people as victims of hate crime.

Control of the research

Control of the research was retained within DITO and the researchers did not feel that there was any interference from the local authority commissioners. The two researchers controlled the whole process and met up regularly to discuss who would be the key figures to talk to. They became part of the Race and Hate Crime Inter-Agency Forum, the hate crime co-coordinating body, on which sat representatives from housing, social services and health and youth and community groups, inter-faith forum and the police.

Shamash said it was important that the research was undertaken by disabled people:

“

It means that people who are likely to be on the receiving end of hate crime can take some ownership of acknowledging that process.

You're making sense of it through what you go through, it's not something that's 'out there'.

”

He saw it as operating at several levels: not only is it your lived experience but also your understanding of the nature of that lived experience, as well as enabling people to look at the wider implications for local policy.

He said that research has an important role to play within an organisation like DITO, in helping to describe and reflect upon the processes that define people's lives. Whilst it gives practical things like credibility and funding, he also saw it as formalising the organisation's understanding of people's lives, something they were already doing but on an informal basis. 'You're democratising the research process.'

Things that helped the research

- The timing was right; there had been some recent publicity about disability hate crime and the organisation Scope (disability charity for children and adults with cerebral palsy www.scope.org.uk) had published a report on the subject.
- As a research team, Shamash felt they were flexible; he felt it was important that they went into it with an open mind and a willingness to participate rather than creating resistances unnecessarily.
- Funding from the London Borough of Tower Hamlets; and DITO as an independent organisation led by disabled people able to undertake the research.

Things that made the research difficult

- There were few difficulties overall, although they would have liked the questionnaire to have reached more people. More forward planning might have helped to get a larger sample.
- More thought could have been given to disseminating the results of the study more widely, but they were used locally which was the original intention.

Making a difference

The report of the study is available from DITO (**www.ditoth.org** Tel 020 7364 6564). They won an award for a poster presentation of the project at the Nordic Nations Disability Research Conference 2007. The report was cited in a couple of academic articles (see, for example, Iganski, 2008).

Following on from this project, DITO carried out a publicity event and produced some materials, which may be found on this website: **www.disablism.co.uk/**. This is the website version of the 'Hate Crimes against Disabled People' information pack; it explains what hate crimes are and gives information about how to report them in Tower Hamlets. This also involved setting up DITO as a third party reporting site for disability hate crime. The project won a London Borough of Tower Hamlets Community Award.

Since the project, the London Borough of Tower Hamlets has developed its policies on hate crime including disability hate crime, and they refer to the study in the Hate Crime Manual on their website (**www.towerhamlets.gov.uk/lgs/1101-1150/1133_hate_crime.aspx#Usefuldocuments**).

Further information

DITO (Disability Information Training Opportunity) is a disabled persons training, rights, employment and community resource run by disabled people based in Mile End, East London.

www.ditoth.org Tel **020 7364 6564**

Example 5:

The Rainbow Ripples report: The needs and hopes of lesbian, gay and bisexual disabled people in Leeds

Summary

This research was undertaken by a small group of lesbian, gay and bisexual (LGB) disabled people in Leeds called Rainbow Ripples, supported by the Leeds Involvement Project. The Leeds Involvement Project is a service user and carer organisation with the aim of enabling those who use community care services to take control over their own health and social care needs. They support a range of groups across Leeds to voice their views about services to local service providers. The research was funded by Comic Relief and undertaken by a disabled academic researcher based at the University of Hull. The research explored and documented the experiences of LGB disabled people in Leeds, their hopes and needs for services as well as the views of service providers. Follow-on funding was obtained from the Big Lottery with the aim of implementing some of the recommendations.

This case study is based on a group interview with four people: a former manager of Leeds Involvement Project, two members of the original Rainbow Ripples group which has now formally disbanded, and the woman employed as development worker for the implementation stage: Lucy Wilkinson, Doug Paulley, Dorothy Mallon and Quinn.

Origins of the research

Rainbow Ripples was originally set up to campaign for the rights of LGB disabled people in Leeds through the Leeds Involvement Project as a self-organised grassroots group. Rainbow Ripples originally employed a worker with the funding from Comic Relief, but after she left they decided to use the remaining money to fund a piece of research: 'Somebody needed to tell the story of our lives as LGB disabled people.'



We know what the issues are, we know how life is, but you have to have the paper to prove it before you can start influencing things.



The group decided to contract with someone to do the research on a traditional tender basis, partly in order to have more control over how the money was spent and partly in the hopes of gaining evidence for obtaining further funding. They put the research out to tender and appointed Ruth Butler at the University of Hull, a disabled lesbian academic researcher.

The research

The research entailed 20 interviews with LGB disabled people who live, work and/or spend leisure time in Leeds; 5 interviews with key service providers; and a questionnaire survey of 437 service providers in Leeds (of which 60 questionnaires were returned). The group and the Leeds Involvement Project had a commitment to the social model of disability; hence, the research was structured on the basis of the twelve demands of the independent living movement in order to reflect the experiences of disabled people in the disabled people's movement: 'Setting our own agenda, working in your own paradigm rather than somebody else's language even.'

The twelve demands of the independent living movement are: Education and Training; Transport; Technical Aids and Equipment; Housing; Personal Assistance; Employment; Advocacy (advice and support); Counselling; Health Care; Community and Social Life; Leisure; Safety, Harassment and Discrimination (Adapted from Southampton Centre for Independent Living, 2006).

The steering group met on a monthly basis for long discussions about the ethical issues, interviews and analysis. It was intense work, revealing some difficult ethical and political issues around disability, sexuality and identity. At the heart of the research were the conflicting attitudes facing people who embody these two different areas of life experience:

“

...the way disabled people are viewed as not having any sexuality as against LGB being all to do with sexual orientation and sex. And so for some people, LGB and disabled is seen as an adult safeguarding issue... the whole thing is seen as very sordid.

”

Control of the research

The group had overall control of the research, although it was contracted out to an academic researcher. From the outset, Rainbow Ripples made it clear that they were to have control over the research, and the researcher and the University agreed to these terms. That they had control was described as 'key' and 'integral' to the project. One of the members of the group described her previous experiences of research where, although it was intended to be user-led or user-controlled research, the local authority had ultimate control of the research and it felt as if service users were there 'to give them some cred.' The fact that it was a project led by LGB disabled people about LGB disabled people meant that:

“

...there was a degree of trust that you're not going to be painted in an adverse way or a way that's not honest, so you're more likely to answer the question in a more honest way because there's not the same degree of suspicion.

”

Also, it meant that they had control over the theoretical context within which the research was placed: it was framed within the social model of disability.

Things that helped the research

- The commitment of the group was clearly a major factor in enabling the project to happen. Despite some major challenges, the research reached completion and was well received.
- Funding from Comic Relief, support from the Leeds Involvement Project, funding from the local authority and from the Lottery enabled the project and its dissemination to run its course.

Things that made the research difficult

- There was a lack of engagement and support from public sector organisations.
- They had some difficulty getting sufficient participants for the research.
- The researcher received threatening homophobic emails, which had to be investigated formally.
- The research meant a lot of unpaid work for the group members: they felt that they had traded off paid involvement for independence because the latter was so vital to them.

Making a difference

The Rainbow Ripples report was launched and sent out to as many organisations as possible. They produced different formats, and placed a summary report, audio version, easy words and pictures version and a British Sign Language video on the website. In the first three months, around 400 reports were distributed or downloaded. It was taken up by the Commission for Social Care Inspection and the Healthcare Commission (now part of the Care Quality Commission: www.cqc.org.uk) and influenced inspection methods. It is also referenced in the Department of Health's (2007) 'Reducing health inequalities for lesbian, gay, bisexual and trans people – briefings for health and social care staff'; Briefing 13: Disabled lesbian, gay and bisexual (LGB) people.

Following the report's publication, the group applied for and received additional funding from the Lottery for an implementation phase. This started with an evaluation of the impact of the report, followed by development of a training pack and then three small projects based on three recommendations. The implementation phase did not get completed in full, due to a breakdown in relations with the 'parent' organisation following a change in management of that organisation. However, the report received national recognition and the group is justly proud of their achievements:

“

We did it as a small group of people; we put our hearts and souls into it.

”

Advice for others:

- Set up an independent organisation. ‘Just don’t ever think you can’t do what we’ve done but also don’t underestimate it.’

“

You can be user-controlled without having to train service users to do the interviewing, by contracting with a researcher as we did. It is important to know that there are different ways of doing user-controlled research.

”

Further information

Rainbow Ripples no longer meet as a group. However, the report is available in standard format, large print, easy read, audio and British Sign Language video on the website:

<http://www.rainbowripples.org.uk/>

Example 6:

Young Researcher Network projects: Get the Life You Want and Have Your Say

Summary

The two projects described here were both led by looked after young people and care leavers. Have Your Say in North Tyneside sought young people's views on the review system for children and young people in care with a view to making it more acceptable to young people. They had the support of the Local Participation Team in North Tyneside. Get the Life You Want (GLUW) in Bradford explored young people's experience of life in care to work out how they could get the life they want. They were supported by the Voice and Influence Team. Both groups were trained and supervised through the Young Researchers Network based at the National Youth Agency

www.nya.org.uk/youngresearchernetwork

Interviews (group and telephone) were carried out with Anthony Read and Elizabeth Goldsborough from the GLUW group, Jason Crawford and Daniel Crawford from Have Your Say, Norrina Rashid from Bradford Voice and Influence Team and Darren Sharpe from the National Youth Agency Young Researcher Network.

Origins of the research projects

These are two of 15 research projects led by young people funded by the National Youth Agency which supported and trained the young people to carry out the research. The Young Researchers Network was founded by the National Youth Agency to support these and other young researchers 'to undertake high quality research to influence and shape children's and youth support services.'

The Voice and Influence Team in Bradford do a lot of peer research with young people. They were trying to improve their contact with looked after young people so when they got the funding, they set up a group of young people in care and asked them what they wanted to research. The group had the freedom to choose any topic, and chose to look at young people in care and how their lives could be improved. They called their project 'Get the Life You Want' or GLUW.

Have Your Say, a group for young people in care in North Tyneside had found that every time they did a consultation with children and young people in care, the review system came up as an issue. They decided to do their research on how young people wanted it improved. They applied to the Young Researcher Network for funding, explaining what the project was, why they wanted to do it and what they needed. The Young Researcher Network then helped with the research proposal and training with interview techniques and other research skills.

The research

1. Get the Life You Want (GLUW) – Making the Lives of Young People in Care Better

The group of young people generated the questions they wanted to ask and narrowed them down in a session with the Young Researcher Network trainer. They used postal questionnaires, focus groups and interviews. The material was typed up and sorted into themes and discussed by the young people in a series of exercises which generated a list of recommendations. The group employed help for the typing and the statistical analysis. At the end of the process the group worked with a professional company to produce a DVD to distribute to young people in care.

2. How Looked after Children are involved in the Review Process (Have Your Say)

Have Your Say reviewed the local and national literature on the review process. From their own experience they generated the questions they wanted to ask and narrowed them down to three main questions: Who controls the review process? Are children and young people's views listened to? How can looked after children and young people contribute to the review process? They held an event to inform people of what they were going to do and an awareness training session for key staff so that they knew about the project.

They used one-to-one interviews and questionnaires with looked after young people and questionnaires given to young people as they left their review meetings. They also gained information from questionnaires for social workers and Independent Reviewing Officers. The information was analysed and recommendations for change generated by the group.

Control of the research

The Young Researcher Network was determined to fund only user-led projects so they carried out a careful support and vetting procedure at the start. They encouraged a discussion from the beginning about how the young people could use the support of the workers and which bits they would need most help with. Both groups were supported by workers as well as by the Young Researcher Network... 'but it was our idea and mainly run by us.'

“

They give you responsibility because sometimes you know more than other adults know because they haven't lived through it.

”

Both groups generated their own questions, analysed the responses and wrote up their findings, all with support. One group described doing the interviews themselves 'with the worker just sitting off to one side.' They were, and continue to be, involved in the dissemination of the findings and recommendations.

Things that helped the research

- The Young Researcher Network and the commitment of local support workers helped the research projects to happen.

“

Young Researcher Network helped us to get training, interview skills training, analysis training, training for proposal writing, questionnaire writing so we've got loads of new skills. We also did training on ethics and public speaking.

”

- The young people also found meeting regularly with their peer researchers from the other projects to be helpful in sustaining their interest and giving them the opportunity to meet new people 'You had someone else to update and ... someone to share things with.'

Things that made the research difficult

- The Have Your Say group did not get enough interviews at first, so they then did some interviews over the phone.
- The young people found that a lot of work was involved over an extended period of time...

“

I were at college at the time. I would get up at 7, finish college 4 or 5 ish and then work with Norrina 'til 8. It were a long day.

”

- The projects entailed additional resources in terms of both staff time and funding from the organisations that hosted and supported them. The small grants (of £3,000 per project) were intended only to add value to existing provision and services.

Making a difference

The Young Researcher Network trainer led a session on identifying the messages from the research, who they should be communicated to and how. The Have Your Say group in North Tyneside presented their findings to Social Services decision makers, heads of service, social workers and was commissioned to make a DVD to be given to all young people when they first go into foster care. The group has now become the local Children in Care Council and has to be consulted by the local authority. It is now starting to engage with younger children.

The GLUW group in Bradford had a big media launch and meetings with the Director of Children's Services and the Head of Social Care. They also took part in a young people's House of Lords debate to share their findings. Two of the seven recommendations have already led to changes and there is a willingness to pick up the other issues.

Both groups have presented at national conferences and the reports have been published through the Young Researcher Network. Both groups have featured in the Newsletter and the Journal of the Social Services Research Group.

Further information

Get the Life You Want: Making the lives of young people in care better by Elizabeth Goldsborough, Anthony Read, Haley Jones. http://www.bkyp.com/pdfs/gluw_report.pdf or contact Norrina Rashid norrina.rashid@bradford.gov.uk

How Looked After Children are involved in their Review Process by J Bradwell, D Crawford, J Crawford, L Dent, K Finlison, R Gibson, E Porter, 2008. Available on the National Youth Agency website (see below).

The Young Researcher Network has produced accessible materials for young researchers, the Young Person's Research Toolkit: <http://www.nya.org.uk/integrated-youth-support-services/young-researcher-network>

Further information available from:
Dr Darren Sharpe, formerly of the National Youth Agency, now Sociologist in User Involvement in Research
d.m.sharpe@hotmail.co.uk

Example 7:

Relationship Matters – Shaping Our Lives

Summary

This project was undertaken by Shaping Our Lives in collaboration with five other user-led organisations (ULOs). The aim was to explore the theme of networking: to facilitate, promote and increase active networking between service users and user-controlled organisations: ‘to build upon the premise that relationships matter.’ It was funded by the Equalities and Human Rights Commission for a one year period.

A telephone interview was conducted with Fran Branfield of Shaping Our Lives, and the report of the five events was used to supplement this information.

Origins of the research

Shaping Our Lives is an independent user-controlled organisation which started as a research and development project but became an independent organisation and national network in 2002. The idea for this project came out of Shaping Our Lives’ National User Group which meets quarterly. This is a diverse group of service users who are networked with local organisations of service users and who feed into much of Shaping Our Lives work. The group is diverse in terms of all equality issues and in terms of their experience of disabling barriers. They identified the need to explore how to improve networking across and between different user-controlled organisations and groups. Shaping Our Lives then applied for funding to the Equalities and Human Rights Commission during an open funding round held in the first year of that organisation’s formation.

The research

The project was undertaken in an innovative way, through the coordination of five regional events designed to collect evidence from service users about their lived experience. Interpreting research in its broadest sense, they saw themselves as ‘collecting knowledge from service users’ through these events. The first stage was to advertise through their network for five groups to organise the events. Each group was then supported to organise its own local event, although they were free to organise them independently. The five organisations were:

- CONTACT, a peer support service for disabled people based in Bradford;
- Disability Wales, the national association of disabled people’s organisations in Wales;
- Gateshead Action Panel, a disabled people’s organisation based in Gateshead;
- One Voice, a disability information service offering information and advice to people in the Lancaster & Morecambe area; and
- Independent Living Alternatives, a disabled people’s organisation based in London, established to promote the right of disabled people to live independently.

Each event involved the group inviting a diverse range of service users and organisations to attend and to discuss the issues, barriers and needs they face in relation to local networking. The focus was on networking across groups and people with different lived experiences. In total, 52 different user-controlled and disabled people’s organisations participated in the events with 82 people taking part.

Some of the groups organised their events without much support from Shaping Our Lives; others needed more support. Shaping Our Lives provided practical items such as guidelines for support workers, event ground rules, guidance for writing the report. Each group wrote up its own event and Shaping Our Lives wrote the final report based on the learning from all five events.

“

Often small organisations only have a small voice, even when they have a very important message to get across. Collaboration and ‘joined-up thinking’ between groups can amplify this voice and increase the possibility of change being effective.

Branfield et al., 2009

”

Control of the research

Control of the project started from the fact that the idea came from service users recognising the need for building on the value of networking and relationship. The project was led and coordinated by a service user-controlled organisation in collaboration with five other user-controlled/disabled people’s organisations. In this sense, the project was entirely controlled by service users, and in addition power/control was shared from the centre to the regional groups. The funders did not interfere with the project during its lifetime, but nor did they give any feedback afterwards.

Control by service users was vital to the project, and was thought to have resulted in empowering experiences for everyone who attended the events. All of them were accessible events with diverse groups of people attending, leading to new connections and relationships based on shared experiences of barriers and a shared desire to work together for positive change.

“

By sharing knowledge we build our capacity.

Branfield et al., 2009

”

Things that helped the research

- The enthusiasm of the local groups carried the project through. Most of them welcomed the opportunity it provided for them to network locally and make connections with new groups and new people.
- Practical support was provided by Shaping Our Lives to the five groups to enable the events to run smoothly.
- People were very tolerant of each other’s different needs and ways of being.

Things that made the research difficult

- It was surprisingly difficult to select the five groups as Shaping Our Lives had a good response to their advertisement at the start of the project.
- One or two of the groups needed a lot of support to enable them to undertake their event.
- This one-year project was seen as the start of something and it was difficult to see it come to an end without further funding or the capacity to follow it through as much as Shaping Our Lives would have liked. A greater emphasis is needed on funding to sustain successful projects; one of the challenges for small user-led and disabled people's organisations is the need to move on and find funding for new projects without being able to build on previous successes.

Making a difference

A full report, including all the reports of all five events, was completed and submitted to the funders. An accessible version was produced and placed on the website. All of the groups who attended the five events joined the Shaping Our Lives network SOLNET (<http://www.solnetwork.org.uk/>).

One of the disappointments for Shaping Our Lives was that they failed to obtain additional funding from the Equality and Human Rights Commission to take the work further; this meant that they were unable to find out to what extent the project had affected all of the local groups involved. However, they continue to work with one of the coordinating groups on joint projects and bids for new work.

Advice for others

- This is a valuable approach for gathering knowledge from service users: people feel that they own the project, can get fully involved and feel that they are making a difference. Shaping Our Lives feel that they have experience in running this kind of project now and are keen to use it again.
- Given the chance to do this project again, they would bring all five coordinating groups together at the start so that they could meet each other and learn from each other.
- Getting the groundwork in place before the start is important; planning for eventualities in advance is an important part of the project's success.

Further information

Shaping Our Lives website:

<http://www.shapingourlives.org.uk>

The report is available from

<http://www.shapingourlives.org.uk/ourpubs.html> or by emailing:

information@shapingourlives.org.uk

Tel: **0845 241 0383**

Text users please use TYPE TALK:

18001 0845 241 0383

Postal address: Shaping Our Lives,
BM Box 4845 London WC1N 3XX

The role and value of user-controlled research

The aim of this chapter is to look across the seven case studies and to draw out common themes as well as differences, in order to inform our greater understanding of the role and value of user-controlled research. Throughout this section, the projects are sometimes referred to by using short labels; these are given in the table below:

	Project title	Organisation	Project label
1	Deaf People's Mental Health Pathways	Vision Sense	Vision Sense
2	Comparison of urine and blood tests for thyroid function	Thyroid UK	Thyroid UK
3	Connect Works (what people with learning difficulties want from personal assistants)	Connect in the North	Connect Works
4	Disability Hate Crime	DITO (Disability Information Training Opportunity)	DITO
5	The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual disabled people in Leeds)	Rainbow Ripples	Rainbow Ripples
6	1. Get the Life You Want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	Supported by the National Youth Agency Young Researcher Network	The Young Researcher Network projects
7	Relationship Matters	Shaping Our Lives	Relationship Matters

1. Reasons for doing user-controlled research

To make change happen

All of the projects were committed to changing or improving the lives of their community of service users, whether directly or indirectly, locally or nationally. As Turner and Beresford (2005) point out, the motivation to make change happen is central to the purpose of user-controlled research. The impact of the projects and the degree to which they succeeded in making change happen is explored further in sections 3 and 5 of this chapter.

To highlight the needs of marginalised groups

This study suggests that user-controlled research often arises from within groups of people frustrated by traditional research that overlooks or excludes them and/or services that do much the same thing. The seven projects powerfully demonstrate the needs and priorities of groups frequently ignored or overlooked by mainstream society, some of whom face multiple discrimination.

“

Somebody needed to tell the story of our lives as LGB [lesbian, gay and bisexual] disabled people.

Rainbow Ripples

”

Several of the projects arose out of the need of a group to describe an aspect or aspects of their lived experience; this is referred to by Turner and Beresford (2005) as one of the ways in which research can emancipate service users.

Through raising awareness of the experiences and needs arising out of their lived experience, groups like lesbian, gay and bisexual disabled people, young people in care, disabled people and Deaf people with mental health needs placed themselves on the map of human experience and were able to exert some influence on local and/or national service or policy development. Connect Works, in exploring the needs of people with learning difficulties in relation to their requirements of personal assistants, raised awareness of their needs and priorities within the context of national policy on personalisation.

No-one else will do it

Closely related to the above, several of the projects were responding to a specific need identified by the group: an issue that perhaps no-one else would know about or be interested in if they did not have the relevant lived experience. The Thyroid UK research is a good example of this, in that it was responding to the frustration of many of their members whose views about the inadequacy of the standard blood test for thyroid disorders have long been ignored by researchers and professionals in the UK. The young people's project 'Have Your Say', in exploring looked after children and young people's experience of the review process is another example of an issue identified out of direct experience. Relationship Matters, in exploring the value of networking across groups of people experiencing different disabling barriers, also addressed a theme unlikely to be a priority for non-service user-controlled organisations.

2. Ways of doing user-controlled research

Control

The extent of control varied across the seven projects and it became evident that the nature and level of control was not easy to deduce from information submitted to the initial mapping exercise alone. Absolute control depended on service users having independent funding (and having control of that funding) as well as a user-controlled organisational base. Two of the examples (The Young Researcher Network projects, Connect Works) originated from within non-user-controlled organisations and their control of the research was not absolute. The groups involved did not have control over the funding themselves but received training and support to give them the skills and knowledge to select their own topic and to undertake the research.



...it was our idea and mainly run by us.

Young Researcher Network

[it was] equal but in different ways.

Connect Works



In both cases, it was clear that the intention of the supporting staff was to enable the groups to have control over the research. Whilst these two projects may have had less control than the others, what they did achieve was to empower service users who had no previous research experience through the process of participation. It is hard to make a judgement on the basis of these seven projects, but this raises the possibility that some groups may benefit from a greater level of support even if it does mean a lesser degree of independence or control.

Although the extent of control varied across the seven projects, having control over the research was seen as vital by all of them. Many of the people interviewed spoke passionately about the significance of having control, both to themselves and to their organisation and their wider community of service users.

It was important to be able to do the type of research they wanted as well as researching the issues they wanted. For some, this was inextricably linked to their commitment to the social model of disability and the importance of carrying out research within the context of their chosen paradigm. One more experienced researcher referred to the essence of having control over the research as 'democratising the research process.' [DITO]

“

It just wouldn't have happened if we hadn't had that level of control.

Rainbow Ripples

Having disabled people doing this is a big thing.

Connect Works

”

The independence of certain projects was slightly compromised by their closeness to local commissioners; what some projects gained in influencing change through this relationship, they may have lost a little in independence. For example, there was some debate over the final report from Vision Sense because of the need for it to be framed in a way to communicate with the commissioners. Equally, Rainbow Ripples, in compromising none of their independence, may not have influenced local services as much as they might have wished. Similarly, Thyroid UK, in taking an entirely independent stance, may not have as many routes as they wish open to them when they come to disseminate their research findings. Again, it is hard to draw firm conclusions about the relationship between independence and influence from this small sample of projects.

Different approaches, different methods

Common to all of the projects was a shared identity between the researcher(s) and the research participants. This has already been highlighted as a common feature of emancipatory research (see Introduction and background), and tends to distinguish user-controlled from mainstream research. This shared identity is closely related to the core motivation of all of the projects to make change happen for others similarly affected by the issues under investigation.

Connect Works and the Young Researcher Network projects involved supporting the development of small groups of service users, whereby people without previous research experience were trained and supported to undertake the research themselves. This 'capacity building' approach is quite common throughout user-controlled, survivor research and collaborative research. It potentially creates the opportunity for the newly trained service user researchers to be empowered by taking part in the research process (e.g. through learning skills and knowledge, and gaining confidence).

DITO, Vision Sense, Rainbow Ripples each engaged individual researchers who shared key aspects of their identity with the service user participants. Rainbow Ripples contracted with an academic researcher to carry out the research on their behalf but selected a researcher who identified as a disabled lesbian and so shared identity with the research participants. The group controlled the research through setting the topics, identifying the questions and becoming fully involved in the analysis and report writing. The researcher brought technical research skills to the project: gaining ethics approval and employing content analysis of the data.

The methods used in the projects ranged from the more conventional use of questionnaires, interviews and focus groups through to more innovative and exploratory methods. For example, in Connect Works, people with learning difficulties facilitated focus groups and used unconventional but necessarily accessible methods of recording and analysing the data. The Shaping Our Lives project (Relationship Matters) took perhaps the most innovative approach to the research; through engaging people in five local events they explored people's experiences of the meaning of networking and relationships. This approach, taking the interpretation of research as 'gathering knowledge' from and with service users, is one they have found to be valuable and are keen to use again.

The Thyroid UK project stands alone in that it was a clinical study, the clinical aspect of which was undertaken in a laboratory on behalf of the organisation. The research was coordinated by a subcommittee of the Management Committee, with the study coordinator being a member of Thyroid UK with personal experience of thyroid disorder.

Organisational base

Five of the projects arose out of user-controlled organisations or groups which had different levels of funding and organisational security (although at the time of writing, Rainbow Ripples no longer meets as a group). They shared a strong ethos of promoting and encouraging the voice and the rights of service users or disabled people. Three of these organisations, Shaping Our Lives, Vision Sense and DITO, have a history of undertaking user-controlled research with a range of different service user or disabled people's groups.

The remaining two, the Young Researcher Network projects and Connect Works were different in that they were supported from within non-user-controlled organisations. However, both retained a strong ethos of supporting and enabling the groups to undertake their research with a significant amount of control and independence.

A common factor across at least five of the groups/organisations was a strong commitment to a social model of disability, which supports one of the potential aims of user-controlled research identified by Turner and Beresford (2005).

Sources of funding

Funding came from a variety of sources: local authority, NHS Primary Care Trust, Lottery, Comic Relief, charity fundraising donations, Skills for Care, the Equality and Human Rights Commission and the National Youth Agency. In some cases, very small amounts of funding were involved: for example, the DITO research received £5,000 and the Young Researcher Network projects £3,000 each (although these were supplemented by extensive support from their 'parent' organisations). It is significant that all of these funders share a remit to promote equality and diversity or to meet the needs of minority groups.

Whilst some of the projects identified a need and then obtained funding for the research (Connect Works, Thyroid UK, Rainbow Ripples, Relationship Matters), others (DITO, the Young Researcher Network projects and Vision Sense) took advantage of a funding opportunity arising out of local policy or service developments or, in the case of Young Researcher Network the funding round announced by the National Youth Agency. In relation to DITO and Vision Sense, local commissioners (the Primary Care Trust or local authority) had identified the needs of a particular group as requiring further exploration in order for service developments to reflect these needs. In each case, the commissioner chose a local independent and user-controlled organisation with whom they had an established relationship, to carry out the work.

3. The benefits

Access and Trust

For most of these highly marginalised groups, it was vital that the research should be carried out by someone who identified as a member of that group. A shared identity between the researcher and participants meant that trust could be established, particularly when conducting face-to-face interviews and focus groups, leading to improved access to participants and to open and honest accounts about the issue under investigation.

For some projects, the increased accessibility that this shared identity brought with it was central to the success of the research. The value of this was illustrated by, for example, a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group. This essence of trust established through breaking down the barriers of power between the researcher and the researched was important to all of the projects. Establishing trust between the researcher and the researched is at the heart of user-controlled and emancipatory research.

“

...when you're interviewed by an academic or someone you don't know you don't have the same level of trust because you don't know what they're doing with that information.

Rainbow Ripples

It's people who know asking people who know.

Connect Works

If it had been someone else, they might not have wanted to talk to an adult. We know how to put things because we've been in care.

Young Researcher Network

”

Quality of the research

The value of a shared identity was also demonstrated when it came to designing the research, deciding upon the questions and analysing and interpreting the findings. The 'insider knowledge' ensured that the research would address the right questions, and be interpreted by people with an understanding of the nature of that lived experience. The importance of this was highlighted by Rainbow Ripples, DITO, Connect Works, and Vision Sense.

“

You're making sense of it through what you go through.

DITO

Adults may not see the same things as an issue, like going to a meeting wouldn't be an issue for an adult because they go to meetings on a day-to-day basis, they might overlook how hard it is going somewhere else but we understand that it would be a big issue. Young people know what to look for because they know what the problems are themselves.

Young Researcher Network

”

Empowerment

“

People take us more seriously. That's what empowerment is. Empowerment: you know you can do it.

Young Researcher Network

”

It is not always easy to articulate what empowerment is, although it is identified as a key principle of user-controlled research. These projects help us to understand empowerment and how user-controlled research can bring about the empowerment for the service users involved. It was most often mentioned in connection with the two projects that involved the support of service users without previous research experience: the Young Researcher Network projects and Connect Works. The young people talked of the opportunity the research had given for them to learn new skills and gain confidence:

“

...lots of training and loads of new skills and I've learnt how to talk to more people... when you know what you're talking about and know how to address people it gives you that confidence.

Young Researcher Network

”

“

I think it's empowered us.

Young Researcher Network

”

Perhaps more significantly, the young people and the people with learning difficulties came to recognise and develop their own expertise, not just through the research itself but also through its dissemination and implementation.

“

If you've lived through it you know more than going to university.

Young Researcher Network

”

The research and the Young Researcher Network gave the young people opportunities to speak at conferences and meet people at a range of events. Connect Works enabled some of the people with learning difficulties to carry out training themselves and to choose their own personal assistants. Empowerment, then, reached out beyond the research and into people's lives.

“

It wasn't just the research, it's opened lots of doors for us, we got involved in all sorts of other stuff...go to all sorts of places you wouldn't ever have gone to, like the House of Lords.

Young Researcher Network

I want to be able to choose who I want to look after me, rather than have others controlling me.

Connect in the North

”

Making change happen

Amongst these seven case studies are some excellent examples of user-controlled research making a difference. As stated earlier, all of the projects were committed to making change for the benefit of their community of service users. What is perhaps surprising is the degree to which they achieved this, given their scale and the size of their budgets.

The close relationship between Vision Sense and the commissioners in the Primary Care Trust, ensured that their service evaluation was able to influence the development of services for D/deaf people with mental health needs. From the start, they knew that there was funding available for implementing the findings, but this example also raises the importance for some projects of having powerful allies (which is also the case for Thyroid UK).

Both Rainbow Ripples and Connect Works obtained additional funding for implementing their findings (from the Lottery and Skills for Care, respectively); both included the development of training packages. DITO obtained additional funding for dissemination that included an information pack and accessible website on which to host it. In addition to this, several of the projects were able to inform national policy in some way (see section 5 in this chapter).

Credibility

Several of the projects talked of the importance of establishing credibility through carrying out the research, whether for their organisation or for their community – or both.

For small user-controlled organisations struggling to sustain themselves in a difficult financial and political climate, this was particularly important. Vision Sense had previously achieved credibility through obtaining a service level agreement with the Primary Care Trust on the advice of the commissioner. However, both the researcher and the Vision Sense lead felt the need to take further training in research skills subsequently, in order to improve their credibility to undertake similar projects in the future. DITO also valued the credibility gained through undertaking the research as well as the opportunity it gave for them to formalise the organisation's understanding of people's lives.

4. The challenges

Resources

It became evident that, in nearly all of the projects, individuals and organisations had contributed additional resources over and above the funding they had received. Some contributed their time and skills for free because of their commitment to the research (e.g. Thyroid UK, Rainbow Ripples). Similarly, other organisations subsidised the available funds, whether in terms of actual money or staff time or both, in order to ensure their success: e.g. the Young Researcher Network projects, Connect Works.

It has been pointed out elsewhere (Faulkner, 2004; Turner and Beresford, 2005) that adequate resources are needed to do this kind of research well. Some needed resources to increase and improve accessibility for service users with particular dis/abilities or use of language, both at the research and at the dissemination stages. Some needed additional resources in the form of training and ongoing support in order to be able to undertake and complete the projects successfully.

Shaping Our Lives was disappointed that they could not get the additional funding to secure and develop the newly-formed networks established by Relationship Matters. A lack of capacity in small user-controlled organisations can often mean moving on to the next project without being able to build on the successes of those already completed.

Discrimination

That many of these projects represented people facing multiple discrimination has already been mentioned (see section 1 in this chapter). For at least two researchers, this became a very real part of the research process. The Rainbow Ripples researcher received threatening emails in response to publicity about the research and the disabled researcher for DITO was verbally abused by a member of the public as he left one of the interviews. Similarly Thyroid UK, in addressing a minority issue in the field of thyroid disorders, was subject to a complaint made to the relevant Research Ethics Committee.

These experiences reflect the very issues that many of the projects are seeking to address, and powerfully emphasise the importance of planning in support for service user researchers, particularly lone workers. The importance of establishing good supervision and support from the start of a project is also indicated by the other challenges people faced during the course of these projects.

Identity and power

Having control over the research did not necessarily mean that issues of control and power were predetermined or unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. Gaining people's trust through identification could lead to people asking more of the researcher than they could perhaps offer, or to some discomfort on the part of the researcher about their role and the power they had therefore adopted. For example, the Deaf researcher for Vision Sense struggled with issues of power and control. She felt ambivalent about the power she held as a result of her role in relation to the interviewees and at the same time felt relatively powerless in relation to the commissioners of the research.

“

This research has spurred me on because we need evidence for future funding for projects. I want to get my research skills up, report writing and things but I am aware that I'm growing in power. I've only realised it recently because of getting into emancipatory research. It's like I'm being paid, but you [interviewee] are the one who is still having to go through it.

Vision Sense

”

For the project to be truly emancipatory in relation to the participants, to engage them more fully in the project, would have needed more resources in terms of both time and money and, she felt it might have meant failing to obtain approval from the ethics committee.

Distress

A shared identity could also lead to emotional distress on occasions, where an individual's personal experiences were remembered or relived through interviewing others. This happened for one of the Connect Works researchers, but she said she felt well supported by the group with whom she was working.

5. The impact

The impact of the completed projects in this sample was disproportionate to their size and scale: in short, they 'punched above their weight.' This was largely due to a strong commitment to maintaining a focus on implementation from the beginning, and a proactive approach to making significant links and making use of networks. Connections with powerful allies were made or taken advantage of, some projects obtained further funding in order to ensure implementation and others were linked directly with local commissioners.

Impact on service users

There were many (predominantly positive) ways in which the research impacted upon the service users involved. As we have seen, some people talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research (Vision Sense; the Young Researcher Network projects).

The impact of the research on the wider service user communities is rather more difficult to quantify, although some of the projects resulted in tangible outputs which had that aim in mind:

- Vision Sense produced an improved pathway through mental health services
- Connect Works resulted in a training programme for personal assistants led by people with learning difficulties
- DITO produced an information pack and dedicated website
- Rainbow Ripples resulted in a training pack and accessible formats for their findings
- Young Researcher Network projects produced DVDs for young people in care
- Shaping Our Lives developed the seeds of new service user networks around England and Wales as well as an accessible report.

Impact on the research

All of the projects mentioned the positive impact of service user control over the research in a number of ways, many of which have been mentioned already:

- increased access to research participants
- a relationship of trust between researcher and researched leading to a greater level of openness and honesty (less suspicion)
- improved accessibility for participants – and hence, inclusivity
- selecting topics and asking the right questions, based on ‘insider knowledge’
- more relevant analysis and interpretation of findings, based on a service user perspective
- dissemination that reaches the service users from whom the research originated (e.g. training by people with learning difficulties; accessible formats for findings to reach people with different disabilities).

Impact on services

Many of these projects had achieved what they set out to do, in making change happen. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development. Notable amongst these are the Young Researcher Network projects, DITO and Vision Sense.

Vision Sense stands out here in that it was closely connected with the commissioning cycle which had designated funds available to implement their findings. DITO was also connected with local commissioners; some of their recommendations were taken on board, they became a third party reporting site for disability hate crime. The Young Researcher Network projects also had an impact locally: Have Your Say made a DVD to be shown to children on entering foster care and they have become the local Children in Care Council. Two of the recommendations from the project Get the Life You Want project have been taken up by local services: two extra workers have been appointed to the fostering and adoption unit, in order to be able to do more family work, keeping in touch, sibling issues; and there are negotiations with the contracted provider about the location of tenancies to help avoid placing young people in difficult areas of the city.

Several projects were able to make use of their relationships with powerful allies to impact on change. The Vision Sense project worked closely with a Deaf commissioner, who was able to understand the issues and politics surrounding the culture of Deaf people; Thyroid UK had a medical ally to assist them with their research as well as a wealth of expertise amongst their members; the National Youth Agency’s Young Researcher Network acted as an ally in enabling the successful dissemination of the Young Researcher Network projects.

Impact on national policy

Some of the projects managed to have an impact on national policy, whether by virtue of their efforts at disseminating the findings, or through support from their funding body. Recommendations from the Rainbow Ripples report entered the Commission for Social Care Inspection inspection guidelines. Connect Works, through dissemination via the Skills for Care website may have had an impact on personalisation policy in relation to people with learning difficulties. The young people's projects were enabled to disseminate their findings at a national level through support from the National Youth Agency's Young Researcher Network, including taking part in a House of Lords' debate.

Conclusions

This section contains the key messages from this detailed exploration of seven user-controlled research projects.

1) These seven projects powerfully demonstrate what can be achieved by small organisations or groups of service users on sometimes very small budgets:

- most had found creative ways of ensuring that the findings reached the people that mattered, some through obtaining additional funding and some through their relationship with powerful allies.

2) The projects were motivated by the desire for positive change:

- to improve the lives of service users
- to improve services or influence policies that will affect the lives of service users.

3) These seven projects highlight the potential of user controlled research to raise awareness of the needs of groups and people often ignored or overlooked by mainstream society, creating opportunities to:

- describe and account for their lives, and to
- identify and explore specific needs not addressed by mainstream research.

4) The projects highlight the potential of user-controlled research to create the conditions for empowerment through:

- equalising the relationship between researcher and researched through a shared identity
- establishing trust with research participants
- enabling service users to participate in the research process with training and support
- leading to positive change.

5) The challenges they faced were common to many research projects involving service users:

- issues of identity and power, personal distress and inadequate resources
- however, a few of them also faced incidents of direct discrimination during the course of the research
- these challenges indicate the need for user-controlled research projects to establish support strategies to sustain them through difficult times.

6) The things that helped them to succeed included:

- passion and commitment
- funding
- good support and training
- support of powerful allies.

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Appendix A: List of questions

Origins of the research project:

1. Where did the idea come from originally – or from whom?
2. How did it develop into a research project?
3. How did it get funded – and what was the influence of funders?

What makes this project ‘user-controlled’?

4. Who and how were service users controlling, leading and/or carrying out the research?
5. Is the project based within a user-controlled organisation or group?
6. Does it have support from non-service users?
7. What differentiates this research from research that involves service users: (do they have experience of both?)
 - a. If so, what are the differences and similarities,
 - b. ...advantages and disadvantages?

Process:

8. How was the research designed and planned – and by whom?
9. How was the project managed and run?
10. Was it influenced by any outside agencies – e.g. funders, etc. ?
11. Who carried out the research?
 - a. Methods
 - b. Training
 - c. Support
12. What approaches appeared to work for the project?
13. What have been the ‘facilitators’ for the project? What key features helped to make the research successful?
14. What have been the barriers – and how were they overcome?
15. Were there any ‘turning points’ or changes of direction? (why?)
16. Did any difficulties emerge along the way – and how were they overcome?

Impact of the project:

17. Whether the intended impact of the research was achieved and what actually happened, including explanations for these impacts.
18. What was the impact of the user-controlled research on those participating in the research?
19. Has taking a user-controlled approach added value to the research? (if so, how)
20. Did the research come up with ‘different’ outcomes or results as a result of being user-controlled (as against a collaborative or non-user run project)?
21. Have any publications emerged from the research? What – and can we have copies...?
22. What influence on practice has the research had – if any?

Learning from the experience:

23. Would you do anything differently if you were starting the project knowing what you know now?
24. What suggestions or recommendations would you make to others about to embark on something similar?

Appendix B:

Members of the Project Advisory Group

Rosemary Barber

Honorary Senior Research Fellow,
University of Sheffield and member of INVOLVE

Mary Nettle

Mental Health User Consultant
and member of INVOLVE

Lucy Simons

Public Involvement Advisor, INVOLVE

Further information

This report is supplemented by:

A summary report: Faulkner A. (2010)

Summary Changing our worlds: examples of user-controlled research in action,
INVOLVE, Eastleigh

An easy version of Example 3: Faulkner A.
and Connect in the North (2010) **Easy read
version: Connect Works – Connect in the
North,** INVOLVE, Eastleigh

We have also produced a series of short films
available on DVD and our website. These
include one film about user-controlled research
and four short films presenting the examples of
user-controlled research.

This publication is one in a series. Other titles
available are:

Blackburn H., Hanley B. and Staley K.
(2010) **Turning the pyramid upside down:
examples of public involvement in social
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Please see page 59 for a DVD
which includes a 15 minute film
about user-controlled research
and short films about four of the
examples described in this report.

Disclaimer: The views and opinions expressed in this publication are those of the authors
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This report provides a clear guide to user-controlled research. The detailed examples address the practical considerations for user-controlled projects and will help others to steer clear of potential pitfalls and complete successful projects. They show the value and range of evidence that user-controlled projects can produce. And the key message coming from all the projects described is that improving health and social care services is the fundamental purpose of user-controlled research.

Michael Turner

Co-author of User-Controlled Research – it's meanings and potential
(now based at the Social Care Institute for Excellence)



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Supporting public involvement
in NHS, public health and
social care research

ORIGINAL ARTICLE

Learning about service user involvement in mental health research

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Abstract

Service user involvement in mental health research is a relatively new concept for health professionals. The aims of this paper were to investigate: how far service user involvement in mental health research appears to have been understood, how far it is happening, reasons why service users get involved in research, and barriers to closer involvement from both service user and researcher perspectives. The literature was examined to explore the extent of service user involvement in mental health research, and ways in which service users are carrying out research. It was concluded that while there is little empirical research in this area, increasingly service user involvement in mental health research can be found in the peer-reviewed domain, and at all levels of the research process. The alternative literature (including what is commonly called the grey literature) offers a rich source to learn from. Consideration of the barriers to closer service user involvement highlights likely challenges to traditional researcher-led ideologies and processes.

Declaration of interest: None.

Keywords: *User involvement, mental health, research*

Introduction

The notion of service user involvement in planning and developing mental health services is well established, and has been supported in the UK by policy directives from the Department of Health (1999a,b). Despite a long tradition of espoused support for service user involvement, there is little evidence that it is widespread in the NHS (NIMHE, 2003; Peck, Gulliver, & Towel, 2002). The reasons for this are complex, and include scarce resources, confusion about the meaning and purpose of service user involvement, resistance from professional staff, and an over-reliance on a small number of service users, sometimes to the detriment of their own health (Bowl, 1996; Pilgrim & Waldron, 1998; Crawford et al., 2002; Peck et al., 2002).

Mental health professionals are less familiar with the concept of service users as active participants in the research process, but in other disciplines this is not a new idea. In the disability field and in feminist research ideology, emancipatory research (research with the aim of empowerment at its core) has been around for some time (Barnes & Mercer, 1997). Here it is commonplace for research on women to be undertaken by women, research on

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Dedicated personality disorder services: A qualitative analysis of service structure and treatment process

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Dedicated personality disorder services: A qualitative analysis of service structure and treatment process

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Abstract

Background: In response to concerns about the quality of services for people with personality disorder, 11 new community-based services were set up in England.

Aims: To identify factors that contribute to high quality care for people with personality disorder from the perspective of different stakeholders.

Methods: Qualitative interviews with service users, carers, providers and commissioners of services at each of the 11 sites.

Results: Despite marked differences in the structure of the services, key themes emerged concerning their general approach to service delivery. These include the need to combine psychological treatments with social interventions and opportunities for peer support, and the importance of clear boundaries which are shared by service users. Services need to actively involve users both in managing their crises, and in planning future service developments. Differences in the accounts of stakeholders emerged around the assessment process, provision of out-of-hours care, and the range and type of clients dedicated services should try to work with.

Conclusions: These data highlight factors which stakeholders believe constitute high quality care for people with PD. Services should pay particular attention to supporting clients during assessment process and developing more effective ways to engage people with high levels of personality disturbance and low levels of motivation to change.

Keywords: *Personality Disorder, health services, qualitative research*

Introduction

People with personality disorder (PD) have maladaptive patterns of relating to self and others which have negative consequences for the individual and society at large. It is estimated that 5% of the general population have a PD (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006). Previous studies examining the experiences of people with PD show that many feel dissatisfied with the care they receive (Haigh, 2002; Ramon, Castillo, & Morant, 2001). Concerns expressed by service users are supported by data from healthcare providers that demonstrate wide variation in the extent of service provision for people with PD. For

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Service user researchers played a key role in the recent evaluation of the pilot community projects for people with a personality disorder diagnosis in England

Learning the lessons together

KEY WORDS

Personality disorder
Service user-led research
Evaluation
Ethics
Inclusion

This article reports on an innovative user-led research project carried out by the Mental Health Foundation as part of a national evaluation of community-based services for people with a diagnosis of personality disorder. The article discusses the principles underlying the research, the successes, the challenges and the lessons learnt throughout this process.

Personality disorder (PD) is a much-contested diagnosis. Many people argue that it constitutes an assortment of behaviours that mental health professionals find challenging or simply do not like.^{1,2} Concerns have been expressed about the quality of services for people given this diagnosis.³ Many people working in mental health and social care feel they are unable to help people with a PD diagnosis, and some believe that they should not be offered a service, on the basis that they are not 'mentally ill'.² Service users given a diagnosis of personality disorder have often been dismissed by or denied access to services,⁴ and have sometimes found themselves treated as 'bad' rather than 'mad'.

Amidst this controversy, and with the publication in 2003 of the national policy document *No Longer a Diagnosis of Exclusion*,³ in 2005 the Department of Health funded 11 pilot community-based services for people with a diagnosis of PD across England. These 11 pilot services provided a diverse range of innovative approaches to helping people with a diagnosis of PD, and served areas ranging from metropolitan boroughs to county districts with populations of over two million people. Ten of the 11 services were for adults with PD and personality-related problems, and one was for young people aged 16 to 25 who have interpersonal problems and are judged to be 'at risk of social exclusion'. One service was specifically vocational in nature; another provided services for people with drug and alcohol problems. Most of the pilot services delivered a wide range of services and support; several were based on therapeutic community principles.

The research reported here was part of the national evaluation⁵ of these pilot services, which was conducted in partnership by the Mental Health Foundation, Imperial College London, University College London

and Kings College London. The aim of the evaluation was to ensure that everyone involved would learn from these pilot services, and that the lessons learnt would be translated into recommendations for future service development. The national evaluation involved four phases, or modules:

- an exploration of the demographic and clinical characteristics of people who have been referred to and taken on by the pilot sites
- in-depth interviews with service providers (managers and front-line staff at each of the services), referrers and commissioners
- in-depth interviews and focus groups with service users who are currently using the pilot PD services, service users who have previously used the pilot PD services, and carers of people who are using/had been using the pilot PD services
- a national survey aimed at finding out how service users, service providers and expert authors believe services for people with PD are best organised.

This article focuses on module 3, a service user-led piece of research carried out by the Mental Health Foundation that aimed to hear directly from the people using or receiving these services. Service user involvement in research now has an increasingly strong reputation. The Mental Health Foundation itself has been the source of some of this innovation, with the *Strategies for Living* programme, which ran from 1997 to 2003.⁶ In recent years, the Foundation hosted the *Service User Research Group England (SURGE)*, which drew up guidance for service user involvement in the *Mental Health Research Network*.⁷ Consequently, the Foundation was well-placed to conduct this large-scale piece of user-led research.

Service users were involved on the project advisory group (PAG) from the start, and contributed to the design of the research module and the interview schedules. The MHF research team recruited service users to work on the project on a sessional basis, initially as interviewers but with the intention of involving them in all the later stages of the research. In order to make this work well, the following procedures were undertaken.

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Mental Health and Social Inclusion

Emerald Article: A helping hand: taking peer support into the 21st century

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A helping hand: taking peer support into the 21st century

Alison Faulkner and Thurstine Basset



Alison Faulkner is an Independent Mental Health Researcher, London, UK.

Thurstine Basset is an Independent Trainer and Consultant, Brighton, UK.

Abstract

Purpose – *The purpose of this paper is to review current perspectives on peer support in mental health informed by service user perspectives.*

Design/methodology/approach – *The paper is informed by a literature review and consultations with five groups of service users engaged in different forms of peer support.*

Findings – *The findings suggest that there are many benefits to service users from engaging in peer support. These include: shared identity; development and sharing of skills; increased confidence; improved mental health and wellbeing; and the potential for challenging stigma and discrimination. Most difficulties encountered were associated with “intentional peer support”, where service users are employed as peer support workers – these included role conflict, setting boundaries, and ensuring adequate training and support. A key theme that divided opinion was the degree to which peer support should be “professionalised” as part of statutory services.*

Practical implications – *The findings suggest that it is vital to acknowledge the different views about peer support that arise in different service user and voluntary sector groups: views about such core issues as payment, equality, and professionalisation. Ultimately, peer support arises from people wanting to create their own support networks; any plans to formalise it from within statutory services need to acknowledge that pre-existing grassroots expertise.*

Originality/value – *Recent developments mean that peer support, which originated from the grassroots of service user experience, has taken a new direction through becoming incorporated into statutory services. This paper looks at some of the benefits and pitfalls of these developments informed by the views of service users.*

Keywords *Peer support, Peer mentoring, Service users, Consultation, Mental health, Training*

Paper type *Research paper*

In the summer of 2010, the national mental health charity Together commissioned two pieces of work exploring the area of peer support. The first was a review of the existing literature on peer support within mental health services (Repper and Carter, 2010). The second was a consultation with users of mental health services about the value of peer support (Faulkner and Basset, 2010). Building on the findings from these two pieces of work, Together then launched their report *Lived Experience Leading the Way* (Basset *et al.*, 2010). This emphasises the positive benefits of peer support and aims to encourage commissioners to support and fund mental health peer support. All three reports are available on the Together web site (www.together-uk.org). This article is based on the learning from these pieces of work. With a particular focus on the consultation with service users about the role and value of peer support in their lives.

A brief history of peer support

Peer support or mutual support has a long and honourable history in mental health. It has been seen to take place wherever service users come together – in inpatient wards, day centres and drop-ins, and in service user groups. People coming together with shared experiences



The Journal of Mental Health Training, Education and Practice

Emerald Article: A long and honourable history

Alison Faulkner, Thurstine Basset

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A long and honourable history

Alison Faulkner and Thurstine Basset

Alison Faulkner is an Independent Mental Health Researcher, London, UK. Thurstine Basset is an Independent Consultant, Basset Consultancy Ltd, Brighton, UK.

Abstract

Purpose – *This paper aims to explore the extensive roots of peer support in mental health, and to identify the values and principles that the authors wish to hold onto as choices are made as to how and whether to engage with formal peer support within the National Health Service (NHS).*

Design/methodology/approach – *The authors attempt to cover the ground of three types of peer support, but with an emphasis on informal peer support and participation in consumer or peer-run groups as providing the roots for the third more formal type, which is often known as intentional peer support (IPS).*

Findings – *Professionalisation of peer support may endanger the equality that lies at the root of peer support relationships. Independence may also be compromised if peer support becomes just another part of mainstream services. Whilst an individual/personalised approach to providing services has many strengths, one must be careful not to remove all opportunity for service users to meet together, support one another, plan and campaign.*

Practical implications – *The findings suggest that commissioners of services should aim for a plurality of peer support and be careful to ensure that informal peer support is flourishing as an essential basis for more formal peer support.*

Originality/value – *The paper shows that, with an increased interest in providing peer support as part of mainstream services, it is important to stress the basic values and principles that underpin informal service-user led peer support.*

Keywords *Peer support, Self help, Shared experience, Values, Mental health, Mental health services, United Kingdom*

Paper type *Viewpoint*

Peer support has a long and honourable history in mental health. Fellow patients and service users have always provided invaluable support to each other, both informally and through self-help and activist groups (Jackson, 2010, p. 14).

Peer support has become the new watchword in mental health in recent years, but the concept has of course been around for a very long time and in many different contexts. Sometimes called self-help or mutual support, peer support has been seen to emerge wherever service users come together: in inpatient wards, day centres and drop-ins and in organised service user groups. It reflects what is perhaps a natural human tendency for people with something in common to come together, share experiences and support each other. Coming together in adverse circumstances, as in the case of some inpatient wards, can create a sense of camaraderie and can be more supportive than the official treatment on offer (Walsh and Boyle, 2009; Faulkner and Layzell, 2000).

Elsewhere in this issue, the focus of discussion is largely on “intentional peer support” (IPS) and the distinction is an important one. Bradstreet (2006) usefully distinguishes between three types of peer support: informal (naturally occurring) peer support, participation in consumer or peer-run programmes, and the use of service users as paid providers of services and supports (or IPS). In the article quoted above, Jackson distinguishes between two versions



The Journal of Adult Protection

Emerald Article: The right to take risks

Alison Faulkner

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The right to take risks

Alison Faulkner

Alison Faulkner is an Independent Service User Consultant based in London, UK.

Abstract

Purpose – Commissioned as part of a Joseph Rowntree Foundation scoping programme, this consultation aims to explore the views of disabled people and service users about risk.

Design/methodology/approach – The consultation reached nine individuals and one focus group, reaching a total of 17 disabled people and service users. Their views were supplemented by the literature.

Findings – The landscape of risk and rights is highly complex. Disabled people and service users have quite different concerns about risk to those of the professionals and the regulatory bodies acting on their behalf. Many people talked of the fear of losing their independence, of asserting their rights and the fear of powerlessness in the face of bureaucracy and (sometimes) uncaring staff.

Research limitations/implications – The profile of rights needs to be raised in an accessible and acceptable way: it is necessary to make the language of rights more commonplace. There is a particular need to reach into mental health and residential care services to find ways of enabling people to have their rights realised. The report has implications for risk assessment and risk management as well as for the regulatory bodies responsible in adult social care. Raising awareness among professionals and policy makers about the risks that service users themselves fear and experience should demonstrate just how important it is that the people whose risk is under consideration are involved in the process.

Originality/value – This paper highlights the views of users of adult social care about risk; their views have rarely been documented.

Keywords Risk, Service users, Disabled people, Rights, Independence, Adult social care, Disabilities, United Kingdom, Risk analysis, Social care, Mental health services

Paper type Conceptual paper

Introduction

In 2011 the Joseph Rowntree Foundation commissioned the author to undertake a small scoping exercise: “to look across the landscape of adult (social) care and discuss service users’ perspectives on salient issues associated with their right to decide about the risks they wish take in their lives, but also on their right to be protected from risks’. The full report of the consultation is published on the JRF web site (Faulkner, 2012). This paper outlines some of the issues in relation to risk, rights and responsibility.

In the field of adult social care, there are many people, issues, organisations and regulatory bodies involved in discussions about risk and safety. Questions of responsibility, duty of care, adult safeguarding and capacity come into play. There is the concern about protecting people society has come to perceive as “vulnerable” and yet these same people we want to be able to live full and independent lives and to take the risks that any one might take in an average day.

Practitioners’ views of risk often differ from the views of people using services and the language used to express risk also differs (Carr, 2010). These perceived risks have implications for the safety and the independence of the individual, but they also have implications for the

The full report from which this paper is adapted is published on the JRF website. Particular thanks are due to those people who generously gave of their time and their views in forming the basis for this project. Also to Ilona Haslewood and the Joseph Rowntree Foundation for initiating the project, and to those who commented on earlier drafts and helped to improve this report, particularly: Sarah Carr, Tina Coldham, Suzanne Collins, Dorothy Gould, Melanie Henwood, Ann Macfarlane and Kay Sheldon.



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Institutional conflict: the state of play in adult acute psychiatric wards

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Institutional conflict: the state of play in adult acute psychiatric wards

Alison Faulkner

Independent Researcher and Service User

Introduction

This article seeks to expose the poor treatment of people that is common on acute adult psychiatric wards, through both personal experience and reference to a number of reports and surveys on the subject. Complaint or redress is confounded by the power differential between staff and patients and the 'invalidation' of psychiatric patients' views. The author recommends a number of short term solutions but in the longer term suggests a complete review of the role, status and function of acute care within the mental health care system: it needs upgrading, updating and valuing in its own right.

Background

Acute Care 2004: A National Survey of Adult Psychiatric Wards in England (Sainsbury Centre for Mental Health, 2005) found widespread understaffing with an over-reliance on bank and agency staff, a lack of therapeutic activities and increasingly high levels of need amongst patients. On the same day, the Royal College of Psychiatrists also published a survey carried out for the Healthcare Commission on violence encountered on hospital wards – *The National Audit of Violence 2003–2005* (Royal College of Psychiatrists, 2005). This too makes unpleasant reading. Evidently about one in three patients experienced violent or threatening behaviour during a stay lasting an average of 40 days. Three-quarters of nursing staff reported being attacked, threatened or feeling unsafe.

These findings do not come as a surprise. They replicate the findings of several previous studies, both national and local. Mind's *Ward Watch* campaign report (2004) found that 51 per cent of recent or current inpatients reported being